

The book cover features a collage of various textures and images. At the top, there's a circular pattern resembling a clock face or a map. Below it, a dark, textured shape, possibly a heart or a piece of fabric, is visible. A small, ornate key lies on a light-colored, textured surface in the lower right. The title 'Come Back Early Today' is prominently displayed in the center, with 'Come Back' in a large, white, serif font and 'Early Today' in a smaller, black, serif font.

# Come Back Early Today

A Memoir  
of Love,  
Alzheimer's  
and Joy

**Marie Marley, PhD**  
Foreword by Gregg Warshaw, MD



**Come Back Early Today**

Come Back Early Today: A Memoir of Love, Alzheimer's and Joy  
by Marie Marley, PhD, with a Foreword by Gregg Warshaw, MD

[www.ComeBackEarlyToday.com](http://www.ComeBackEarlyToday.com)

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Editor: Helga Schier, PhD

Cover Design: Julie Beets

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First Edition

ISBN: 978-0-9835706-1-5

Joseph Peterson Books  
PO Box 2674  
Olathe, KS 66063

**Come Back Early Today**  
**A Memoir of Love, Alzheimer's and Joy**

**Marie Marley, PhD**



For Ed

and

For Marjorie Rentz  
and  
Clarissa Rentz





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## Acknowledgments

I want to express my deep appreciation to everyone who supported me during Ed's illness, the subsequent years as I grieved my loss, and the long period of time I was writing this memoir. Special thanks go to Marjorie Rentz, MSW, Helpline Coordinator at the Cincinnati Chapter of the Alzheimer's Association; Clarissa Rentz, MSN, former Executive Director of the Cincinnati Chapter of the Alzheimer's Association; and Irene Moore, MSSW, and Doug Smucker, MD, both of the University of Cincinnati Department of Family Medicine.

I will always be grateful to the staff at the Alois Alzheimer Center in Cincinnati for the care, respect and affection they gave Ed while he lived there. Specifically, I want to thank Susan Gilster, PhD, Executive Director; Kristi Guilfoyle, Director of Admissions; Ann Huffman, MSW, the Center's Social Worker; Jan Roark of the Activities Department; and all of the wonderful nurses, aides, receptionists, and other staff who provided Ed such warm and competent care.

I want to acknowledge those who helped me prepare the manuscript, including my assistant, Casie Shafer, and my proofreaders, Emily Mosher, MA, and Rebecca McGowan. Special thanks go to my editor, Helga Schier, PhD, and to Bradley Sanchez Houseton for her expert creative and technical assistance.

I also want to thank those closest to me, including Jean Youkers, who provided valuable moral support and suggestions about the manuscript, and I express my gratitude to my two dearest friends, Marsha Jaeger and Teresa Lowen, to whom I am indebted for offering helpful advice about the manuscript. But most of all, I thank them for their years of unconditional love, affection, and patience both with Ed and with me.

### Author's Note

I have written this memoir from my perspective, aiming for an emotional truth and striving for an accurate recollection of events as much as can be possible considering that the events portrayed occurred over a period of thirty-two years. I recognize that some of my memories may have faded or become flawed. Some persons have been omitted from the book and a few residents are composites of more than one actual person. Finally, the names of several people, including all of the Alois Center residents, have been changed to protect their privacy.



## Foreword

In this fast-paced engaging memoir, Dr. Marie Marley relates vividly and honestly the challenges faced by caregivers of loved ones with Alzheimer's disease, a condition that currently afflicts 5.4 million Americans. The statistics for these patients' caregivers are even more alarming. The Alzheimer's Association estimates that nearly 15 million family members, friends and neighbors are currently providing care to patients with Alzheimer's and other dementias. The toll on caregivers is great. Their experience significantly increases their emotional stress, jeopardizes their physical and mental health, and can negatively impact their employment and finances. There is a critical need for information about how to approach the daunting problems these committed individuals face.

This compelling love story offers hope and help to those moving along the path of what can be an overwhelming journey. The author chronicles her struggle with the complex problems that arose as her life partner, Dr. Edward Theodoru, became evermore demented. These are the challenges all caregivers of Alzheimer's patients typically face, usually beginning with a fierce denial that there even *is* a problem. Following that other issues typically arise, including dealing with the loved one's personality changes (which can be negative or even abusive), suspending driving privileges, managing assisted living and/or nursing home placement, engaging hospice services, and making end-of-life care decisions. Two of the most trying problems for caregivers - problems some never solve - are simply coming to terms with their loved one's condition and finding new ways of relating. Dr. Marley shows us how she overcame her denial, depression and despair and ever so slowly rose to the challenge. In the final chapters she shares the intimate details of her last visits with Ed, during which he was sometimes entirely lucid and freely expressed love, affection and even joy.

I strongly recommend this memoir to caregivers of dementia patients. It will show them it's possible to find new and creative ways to communicate and interact with their loved ones. It will bring comfort to those going through the same experience, letting them know they are not alone, and it will help validate both their positive and negative feelings

about the difficult situation in which they find themselves. This work will also be valuable to health care professionals, giving primary care physicians, nurses, social workers and others a detailed, comprehensive view into a caregiver's life that will provide insights as they care for dementia patients and caregivers in their offices or long-term care settings.

As a family physician and geriatrician who has provided care to hundreds of dementia patients and their caregivers, I found the book's information illustrating approaches to caregiving problems to be practical, insightful, and inspiring. Equally important, *Come Back Early Today* is a true testament to love, devotion and perseverance.

Gregg Warshaw, MD  
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Professor and Director of Geriatric Medicine,  
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## Chapter 1: A Rude Awakening (2000)

### A Crisis

I was deeply immersed in writing a short story about three parakeets, trying in vain to unravel an especially tangled sentence, when I was startled by the phone's strident ringing.

*Must be Ed.*

But it wasn't.

"Hello. Is this Marie Marley?" asked a sweet female voice I didn't recognize. I braced myself, knowing from recent experience that when an unfamiliar voice asked to speak to me, bad news about Ed would likely follow.

"Yes, it is," I answered, turning away from my computer screen.

"My name is Lila Greenwich, and I'm here at the Edgecliff apartment building with Dr. Theo. ..."

"Is he *alright*?" I interrupted.

"I think so. He's a little disoriented though."

"What happened?" I asked, alarmed by her tone of voice.

"He was driving down Victory Parkway on the wrong side of the road. He must have realized it too, because he stopped as I happened to drive by. I was worried so I circled around and stopped behind him, got out and approached his car. He was quite confused so I offered him a ride home. We just got here and he asked me to call you."

"Oh! My God," I said, slapping my hand to my head, hurting my ear. "Thank you so much!"

*He could have been killed. Or killed someone else.*

"His car is still parked out there on Victory Parkway," she continued. "I can take you there if you want to drive it home."

"Of course. I'll leave right now. It'll just take me a few minutes."

I raced to the garage, jumped into my old Civic, backed out of the driveway and floored it. I was really angry. He *knew* he wasn't supposed to drive after dark. He *promised* me.

I tried to convince myself it wouldn't have happened had he not been driving after dark. In my denial I failed to make any connection between that event and the many lapses of memory and other signs of confusion he'd been showing for some time.

When I arrived at the Edgecliff exactly seventeen minutes later, John, the doorman, was waiting for me. He was the friendliest of the doormen, always smiling, and the only one who ever addressed me by name.

"Dr. Marley," he said, "Dr. Theodore is waiting for you in the lobby with a woman and her daughter. I hope you don't mind that I gave her your phone number."

"No, I'm glad you did, John," I said.

I entered the pretentious, cavernous lobby where I found a pleasant, refined-looking African American woman and a strikingly beautiful teenager sitting with Ed on the overstuffed sofa. He was 5' 8" and only 120 pounds, and the enormity of the sofa engulfed him. He looked dazed, confused and even a little scared.

"Oh, Kitty!" he said when he saw me. "I'm r-r-really glad you're here," he continued, sitting up a little straighter. "But I'm amazed! How did you know r-r-right now to come here? This nice lady just brought me home. I was lost."

"Yes, I know. You told her to have *John* call me," I said, hoping I was hiding my anger, not so much from him, but from the kind strangers who had saved him.

"Oh, I see. I forgot," he said. Then he leaned back into the sofa cushion.

I introduced myself to Mrs. Greenwich – Lila, she told me to call her – and shook her hand. She was in her early 40s, and a mild pleasant fragrance wafted in the air around her. Medium height and weight, she was wearing a long black skirt, stylish high-heeled boots and a patterned black and white blouse under a gorgeous brown wrap. Her smile betrayed that she was the kind of person who'd stop in the



dark of night to help a total stranger. And of course, that's precisely what she had done.

Tanya, her daughter, was less ethnic in appearance except for her intricately woven hair. She was wearing jeans, sneakers, and a royal blue sweater. Her light blue down vest lay crumpled on the sofa. There was a well-worn book bag at her feet, and she looked up only briefly from the paper she was reading when her mother introduced her. Her mother's Good Samaritan behavior was obviously interfering with her homework. Somehow I got the impression that might be a frequent problem.

Frankly, I wouldn't have done what Lila did. Ed lived in an upscale apartment building, but it happened to be in one of Cincinnati's worst neighborhoods. If I'd seen an old man pulled over on the wrong side of the street after dark there I'd have thought he was either drunk or on drugs. And I probably would have been right. It was just incredible that there were still such brave, caring people as Lila in the world. While it might ruin her study schedule, Tanya was learning a lot about the Golden Rule at a young age.

"You're Dr. Theodore's daughter, I assume?" Lila asked.

*Everyone asked if I was Ed's daughter.*

At 50, I was certainly young enough to be his daughter, but I wasn't. I should have said, "No. He's the love of my life." But instead I gave my stock answer.

"We're best friends."

Of course, "best friends" didn't even begin to explain our relationship.

Lila and I got into her black Escalade to drive to Ed's car while Tanya stayed behind to finish her homework.

"He has the most charming accent. Where's he from?" Lila asked as I fastened my seatbelt.

"Romania," I said.

"Romania," she repeated. "I don't think I've ever met anyone from Romania. How does he pronounce his last name?"

"It's 'Tay-oh-door-oooh,' but Americans have trouble pronouncing it so he usually introduces himself as 'Dr. Theodore,' but that just confuses people because he can't pronounce 'th,' so it comes out 'Tee-oh-door.'"

"Tay-oh-door-oooh," she said, as though practicing it. "What a delightful gentleman he is! He's so sweet. How long have you known him?"

"Oh, about twenty-five years."

“Twenty-five years! Wow! How did you guys meet?”

She seemed fascinated by our relationship. Given our enormous age difference, I’d never quite felt comfortable telling people our story, but somehow Lila put me at ease.

“We met at the University of Cincinnati back in 1975,” I said. “My history professor introduced us. When we first met he was such a perfect gentleman, he even bowed formally before shaking hands.”

“Quite the gentleman,” Lila said.

“Yes, a gentleman and an incredibly brilliant scholar – with a PhD *and* a law degree. He also had a booming bass voice, that charming Romanian accent and a curious smile. I was intrigued by that smile.”

The bit of information I couldn’t tell a perfect stranger was that Guido, my history professor from Italy, wasn’t just one of my teachers. We’d been having a passionate love affair for seven years. Introducing me to Ed was the worst and last mistake he made in our relationship.

“Ed and I were lovers and lived together for three years,” I continued. “Then we broke up but became inseparable friends. Life partners. Soul mates.”

“All those years! What a remarkable love story,” Lila whispered, appearing to grasp the nature of the relationship.

“How old is he anyway?”

“*That’s* a state secret,” I said, my body tensing up.

I always dreaded that question.

“Oh, you can tell *me*,” she said, glancing over and smiling.

“He’d kill me.”

“I won’t tell anyone. I promise.”

I knew better; and I knew he really would kill me if he found out I told her – or anyone else for that matter. But I couldn’t resist giving her a hint. I was kind of proud that he didn’t look anything near his age.

“Don’t *ever* repeat this,” I said. “He says he’s 77 but he’s really older. I can’t tell you how *much* older.”

I was immediately sorry I’d told her. I felt like an ‘eed-yut’ as Ed pronounced it. He’d sworn me to secrecy and here I was betraying him to a total stranger. At least I hadn’t told her he was actually 87.

I changed the subject.

“I love him dearly but I’m livid that he was driving after dark,” I said. “I’ll have a serious talk with him when I return.”

Anger permeated my voice.

“Now, Marie dear,” she said, patting my knee and speaking compassionately. “Don’t be mad at him. He couldn’t help it. He’s a very sweet, adorable gentleman. You be good to him, you hear, darlin’?”

She didn’t seem to understand the seriousness of the situation. But I didn’t want to contradict that wonderful woman so I promised her I’d be sweet.

*Good thing she won’t be around when I talk to him.*

We arrived at Ed’s ancient – 1984 – silver Accord and I successfully maneuvered it onto the proper side of the street. I was half frozen, because in my haste I hadn’t put on a coat before leaving home even though it was a bitterly cold evening. I followed Lila back to the Edgecliff, where she pulled up under the ‘grand portico’ to pick up Tanya. While Tanya was getting into the Escalade I parked Ed’s car in the parking lot – the ‘platform’ he called it – to the left of the building. I rushed back to thank Lila one more time, squeezed her hand, said good-bye, and waved as they drove off, all the while figuring out what I was going to say to Ed when I got upstairs.

### **Stop Driving for God’s Sake**

I got angrier by the minute as I went up to the ninth floor. Coming off the elevator, I saw that Ed’s apartment door was ajar. He often left it like that when he was expecting me. I stomped in, flinging his car keys down on the little drop leaf kitchen table he’d bought at Goodwill when he first came to the U. S. He was sitting in his recliner, the TV blaring with Fox News coverage of the Supreme Court’s deliberations over the presidential election. A water glass half full of vodka was sitting on the little side table next to his chair. He’d long ago outgrown shot glasses and had begun using water glasses when he wanted a drink, a practice that had been alarming me for years.

While I was gone he’d changed from his navy blazer and dress slacks into his ‘house clothes’ – threadbare washed-out dark blue slacks with stains that wouldn’t come out, a pitifully wrinkled blue shirt, and worn-out house slippers. This pathetic ‘uniform’ always seemed to relax him and bring some comfort. When he was still teaching at Northern Kentucky University – just across the river from Cincinnati – from which he’d retired several years earlier, he wouldn’t have been caught dead dressed like that, even at home. Back then he never left his apartment without a stylish sport coat and tie – not even just to go to the

lobby to check his mail or to the basement to do his laundry. In fact, he once told me he had a nightmare in which he was at Kroger's without a tie.

I resisted the urge to slam the door.

"Why were you driving after dark?" I asked, towering over him and putting a piece of Nicorette in my mouth. "You know you're not supposed to drive after dark."

"I know, Kitty," he said plaintively, looking up at me.

'Kitty' was the pet name we called each other. It was based on the generic name I'd given my cat. Ed loved Kitty and for whatever reason had started calling me '*Little* Kitty.' One day I asked him if I was 'Little Kitty,' then who was the cat 'Kitty?' I laughed out loud when he immediately said she was 'the *Very* Little Kitty.'

"Well, what *were* you doing driving?" I demanded.

"I went to Servatii to get some Italian bread and when I came out it was r-r-raining hard. I didn't want to drive in the r-r-rain home so I waited until it stopped. But by then it was dark. So I *had* to drive in the dark. I got 'meexed' up. I turned on the wrong street and got lost. Would you like a drink?"

He was visibly shaken; like a poor little child trying to explain to his mother that whatever happened wasn't his fault and she shouldn't be mad. His hands were literally shaking, but that in itself was not significant. Ever since I'd known Ed his hands had been unsteady. When he held papers they fluttered. A cup of coffee would quiver in his hands. The doctors didn't know why he had the tremors but had ruled out Parkinson's or anything else serious. Although I usually refused his offers of vodka, I accepted that one, feeling the need for a good stiff drink to fortify me for what I knew was going to be a major battle. But I wasn't used to hard liquor and it burned my throat so much that I put the glass down and just left it there.

"Why were you driving after dark?" I asked again, raising my voice. "And turn off the damn TV."

I should have been sweet and loving as Lila told me. He must have been terribly frightened to be lost after dark in that neighborhood. But instead of showing love and compassion, I expressed white-hot anger. I acted as though he'd done it on purpose and needed to be yelled at. But then I realized the cold hard truth and my heart sank.

“Ed,” I said quietly, “you have to stop driving. That’s all there is to it.”

Then he started to yell.

“No! I will never stop driving!”

He abandoned the ‘poor little child’ mode and put his glass down so forcefully that a few drops of vodka flew onto the table.

“You have to stop,” I said again calmly, as conflicting emotions overpowered me. “You’re going to kill yourself.”

“I don’t care ‘eef I ‘keel’ myself,” he said.

“I care,” I said. “And besides, what if you kill someone else?”

He raised his voice even more. “I don’t care about *that* either,” he said, staring a hole through me.

“Ed, you’re crazy! How can you say you don’t care if you kill someone else?” I asked, hardly believing I’d heard him correctly.

“I *don’t* care,” he said, suddenly standing up.

We were facing each other, nose to nose, inches apart.

“I tell you, I will *never* stop driving,” he shouted, wagging his finger in my face.

I’m sure the neighbors heard us, but they were used to this. They’d been hearing us yell at each other like this for years. This was how Ed and I ‘dee-scussed’ things. I wouldn’t yell at other people, but since it was Ed, it was not only allowed, it was expected.

Saying he didn’t care if he ‘keeled’ someone else really upset me. Ed could be bizarre and eccentric, but this statement shocked me.

Our fight escalated, and finally he roared in an ugly guttural tone of voice, “Get out!”

“I’ll be happy to!” I shouted, and slammed the door behind me.

What I didn’t realize was that beneath the angry protests there was probably a vulnerable man worried about getting older; a man spending a lot of time thinking about death. This fiercely independent man couldn’t and wouldn’t accept that the time when he was able to drive himself wherever and whenever he wanted might be over. In his mind, having to rely on others must have seemed like a small death in itself. At the time I wasn’t aware that underneath the tough exterior could be a man secretly frightened that his mind might be slipping. He was struggling to make sense of what was happening to him. Why did he get lost? Why did he drive on the wrong side of the road?

Ed had been showing signs of mild confusion for awhile. At first it had been little things like forgetting his wallet when going to Kroger's and leaving his headlights on when parking at the mall. Twice he'd gotten lost coming to my house. Both times he'd gone to nearby houses and asked to use the phone to call me to come get him. And twice he'd called me early in the morning to report he'd been up all night searching for something he'd lost. Once it was his passport; the other time, his safe deposit key. He never did find either. Then he started mixing up proper nouns, referring to 'Kroger's' as 'Stover's' and the 'Medical Arts Building' as 'the 5/3 Bank.' And he'd confuse the names of people and places. He'd actually started calling ABC's George Stephanopoulos 'George Popadopoulos.' Even though the two names were similar, he *never* would have made that mistake before.

Then he began forgetting to turn off the coffee maker and stove. Little things we all do occasionally, but it was happening to him far more often than to the average person. He routinely forgot the names of common objects (once he called his eyeglasses 'com-poo-ter's' and referred to his hands as 'elbows'); he didn't recognize his favorite talk show hosts' names; and then he even started forgetting where he'd put everyday items such as, unbelievably, his clothes. Sometimes he spoke Romanian to me, and that although he knew I didn't understand a word of it. Then there was this driving problem, but I still didn't connect the dots. I just viewed it as an isolated area of dysfunction – not a sign of early dementia. Little did I know that it was just a matter of time until he wouldn't even remember he owned a car.

Alzheimer's is, above all, an insidious disease. Its symptoms begin so mildly and progress so slowly that it's easy to deny them until one day there's a 'defining incident,' an incident so bizarre that not even the spouse, child or other loved one can explain it away. Years may pass between the earliest occasional confusion and the inevitable 'defining incident.' And during those years, the person may annoy or even anger loved ones by being late, forgetting things, being short tempered and confused, and a whole variety of other troublesome behaviors.

As the afflicted person's brain slowly deteriorates, he struggles to adjust and continue functioning. This alone takes extreme mental effort, often leading to anger and agitation. During this time the person may also be in denial, realizing something is wrong and trying to understand

it in any way possible that doesn't involve the words 'Alzheimer's' or 'dementia.'

In the days, weeks, and months after the driving incident, I asked Ed to stop driving. I begged him to stop. I implored him. Cajoled. Pleaded. Insisted. I ordered him to stop. Sometimes I cried when I talked about it. I alternated that with trying to explain in reasonable terms why he should stop. I talked about it on the phone. I talked about it when we went for walks. When we went out for pizza. On the way home from the movies. I talked about it all hours of the day and night. To no avail. His response was always the same.

"I will *never* stop driving!"

Of course I could have taken away his keys, but he was still alert enough to know how to get replacements made. Finally, when I went to see him one Friday afternoon, I decided to threaten him.

As we were having our usual Turkish coffee I looked him right in the eye and said, "If you don't stop driving, I'm going to report you to the Bureau of Motor Vehicles. They'll make you take a driving test and you know you'll fail. Then they'll take away your driver's license."

*Silence.*

Ed was at a loss for words for the first time in the twenty-five years I'd known him.

*Dead silence.*

We stared at each other.

"Would you like to go to Lenhardt's for lunch?" he asked.

"Sure. I'm starving," I said, deciding to let it go for then.

I had no intention of turning him in. He'd never speak to me again, which would devastate me. I was just hoping the threat would scare him into giving up driving. I'd have to wait and see.

### **Problem Solved**

I didn't see Ed again until the following Sunday, when he asked me to take him shopping for suitcases at Tri-County Mall.

He always wanted to shop for suitcases. It was one of his more quirky features. He was obsessed with suitcases, or 'luggages,' as he called them. Even he admitted it. If we were in a department store and happened to pass by the luggage department, he felt compelled to stop, just as a child is drawn to stop in the toy department. He'd spend a good thirty minutes or so while he examined *each* suitcase. Sometimes he

would buy one only to return it the next day, disillusioned with one feature or another. And sometimes when he'd return one suitcase he'd buy another one, which more often than not would also be returned. Aptly, when he retired from Northern Kentucky University they gave him a suitcase as a retirement gift. Of course, he exchanged it for a different one the next day.

He frequently and shamelessly returned other merchandise, too, even when it had been heavily used. He once returned an area rug to Pier 1 after nearly six months. Remarkably, they took it back despite the date on the receipt. When stores didn't want to take back his used merchandise, he argued so long and so loudly that they'd relent just to get rid of him and avoid a scene in front of their other customers. He was so adept at returning used merchandise, my friends occasionally asked to 'borrow' him to return items for them.

Despite his obsession with buying and returning suitcases, he did own several, arranged neatly in his walk-in closet, standing side by side like sentries, waiting to be called to duty. They were of all sizes, shapes and colors, and with different numbers and configurations of compartments that he loved exploring. I think he enjoyed these investigations more than he loved actually using the suitcases. Most of these bags had locks. He had a stack of stray keys in his desk, but most belonged to suitcases he didn't even have anymore. Nonetheless, every time he packed for a trip he tried every key in every lock.

His self-proclaimed 'mania' with buying suitcases was surpassed only by his idiosyncrasies when it came to packing. 'Making my luggages,' as he called it, was always traumatic because he had a horrible time deciding what to *put* in these suitcases.

He would always drag me right into it. It would go like this:

"Kitty, should I take the blue shirt or the white one?"

"Take the blue one."

"Oh! No! I want to take the *white* one," he'd tell me.

"Okay, Kitty. Then take the white one."

"No," he'd insist. "I really want your *advice*."

"Well, if you want my *advice* dammit, take the blue one."

"But I don't *want* to take the blue one."

And so it would go with *every single piece of clothing* that went into the suitcase. And then when the suitcase was finally packed, he'd start taking things *out*, and start all over again. It had taken the two of us



three excruciating days of packing, unpacking, and repacking for one of our five-day vacations, for which he actually ended up taking four suits, none of which he wore. His ridiculous packing routine was so exaggerated it made him look like a caricature of himself.

‘Making my luggages’ was a phrase that would stay with us forever. In the years to come, whenever he was seriously ill, he’d use this phrase as a euphemism for ‘putting my final affairs in order.’ But during all these luggage shopping trips, packing nightmares and references to ‘putting affairs in order,’ I never would have guessed that I’d be the one to bear the responsibility for ‘making Ed’s luggages’ when the time came for real.

In our early years together I found his obsession with suitcases charming. But by this time, it had become annoying beyond belief. That particular Sunday, about a week after the driving incident, it was unusually sunny and warm for the middle of December. There was not a cloud in the sky. With the sun beating through the windshield, the car was hot and so we shed our coats. But the weather didn’t make the shopping trip any less agonizing. He insisted that we go to three different stores, where he kept store clerks busy showing him ‘luggages’ in different shapes, sizes and colors. I was bored to death. When it was all over, he had bought nothing.

When we returned to the Edgecliff, Ed went into the galley kitchen and I followed on his heels. He poured himself a generous drink and offered me one. I declined and took a Diet Coke from the fridge. We sat down at the kitchen table, covered with black newsprint from his precious *New York Times*. Then he began what sounded like a well-rehearsed speech.

“*Little Kitty,*” he began calmly, accentuating ‘little,’ as he often did. “You have me in the palm of your hand. ‘Eef’ you want as a bad driver to turn me in you can and there is nothing to stop you I can do.” He paused. “But I can tell you r-r-right now, it will cost you tens of ‘tousands’ of dollars. Not ‘*tousands*’ of dollars – *tens* of ‘tousands.’” Then he repeated himself. “*Tens* of ‘tousands.’”

It took me a few seconds to understand, but when I finally did, I burst into laughter.

*He’s threatening to disinherit me!*

That was vintage Ed. It had taken him three days, but he’d finally found a fitting response to my threat.

“Oh, Kitty. Come on,” I said, laughing so hard tears were rolling down my cheeks. “I’m not really going to turn you in. I just wanted to scare you so you’d stop driving.”

“I know you weren’t r-r-really going to do it,” he said. “I r-r-really wasn’t going to do what I said either.”

I never got him to *agree* to stop driving, but I finally did get him to *stop*. Slowly, as time passed, I discovered the solution. One day I was going to Kroger’s and asked if he wanted to come. He said he did and I drove. So I started inviting him every time I went. He was always happy to go and let me drive. Then I started inviting him to various other stores and took him to those, too.

Taking him shopping was not without peril, however, for he was maddeningly slow. At Kroger’s, for example, instead of simply putting a box of spaghetti in his cart, he would pick up a box of every brand of spaghetti and read everything on it. Then he’d compare the prices of all the brands. And he’d repeat this process with every item he bought every time he went. It typically took him three times longer to buy his groceries than it would have taken me to buy them for him.

His increasingly erratic behavior added another layer of issues. Sometimes he’d lose his temper and yell at me for no good reason. And sometimes he behaved inappropriately in other ways. Like once at the salad bar he decided he’d taken too much lettuce, so he picked up some from his plastic container with his fingers and put it back in the salad bar while other people looked on. I was mortified. So eventually I just had him give me a list and I bought and delivered his groceries. It was a lot faster and much less nerve-racking.

Little by little I started running all the errands for this formerly vibrant, self-reliant man. This man who’d always been completely independent; who, though never a *good* driver, managed to go anywhere he wanted, anytime; who sneaked into my house on my birthday every year and left yellow roses on my dining room table.

At that point I was doing pretty much everything for him. I picked up and delivered what he needed from Kroger’s, CVS, Starbuck’s, Servatii, the Public Library, the University of Cincinnati and Northern Kentucky University Libraries, Widmer’s Dry Cleaner, and Barnes and Noble. I took him to his internist, numerous medical specialists, his podiatrist, and his dentist. I drove him to the 5/3 Bank and his lawyer, Stuart Susskind. I took him to buy clothes, shoes, and ‘luggages,’ which he still

wanted even though he didn't travel anymore. These duties were now part of my life. And if I wasn't available, he used his 'driver,' Mr. Ellington – or 'Ellington,' as he called him – a compassionate African American Evangelical Christian who drove a regular cab and would make time to drive Ed to do his errands.

And since I had taken away his *need* to drive, pretty soon Ed stopped driving. In fact, he never drove again the rest of his life. However, in an ironic twist, one year he made me drive him to the Bureau of Motor Vehicles to renew his license even though he hadn't driven for years.

Thus, without even realizing it, I'd solved Ed's first serious dementia-related problem. Little did I know just how many more lay ahead.

## Chapter 2: The Longest Day (2003)

### A Trying Day

One fateful day I had to take Ed to see his internist, Dr. Bibler, because his allergies were acting up. His nose was running constantly and he was sneezing uncontrollably, sometimes six or seven times in a row. It was the dead of winter, 2003. Ed was 90, I was 53. We'd been together 28 years, most of them absolutely blissful, fascinating and breathtaking, but since the driving incident three years before, things were continuing to deteriorate badly. Ed was becoming more and more difficult to deal with, and I didn't know how much longer I could tolerate him. I really didn't. I wasn't aware that he was slowly becoming demented. I was in deep denial – not uncommon among loved ones of dementia patients – and just thought he was becoming incredibly mean.

Before picking him up for his doctor's appointment, I'd stopped at Kroger's to get his groceries. I arrived at his apartment around 10:00 AM with eleven plastic bags of food. When Ed didn't answer his door, I let myself in with the key he'd given me only after a series of long heated debates many years before.

Ed was supposed to be dressed and ready to go, but I found him in his threadbare pajamas and worn-out slippers sitting on the edge of his bed, holding the telephone receiver in his lap while speaking Romanian into the air. I figured he was trying to talk to either the Romanian jeweler or the Romanian housekeeper, two of his old acquaintances. I walked over and physically moved his hand – and the receiver – up to his left ear, the 'good' one. Soon he finished his conversation and put the receiver down on the red plaid blanket on his bed. I hung it up for him.

"Oh! Hello, Kitty!" he said, looking up at me. "I'm so happy you're here."

“Ed,” I said a little curtly, entering the bedroom, where clothes, shoes, books and newspapers were strewn about. “You’re supposed to be ready to go see Dr. Bibler. Why aren’t you dressed?”

“Honestly, Kitty, I forgot I had an appointment with Dr. ‘Bee-bler.’”

“Well, you do. So hurry up and get ready,” I said a little impatiently.

“Certainly! R-r-right now!”

He stood up and began unbuttoning his pajama top. I was relieved that at least he seemed in a good mood.

While he was getting dressed I went into the living room, dropped my Coach bag on the sofa, then wandered into the kitchen to inspect the refrigerator. Sometimes he kept Snickers bars in there for me. The first thing I noticed was a water glass half full of vodka on the kitchen table.

*Jeez, it’s only 10:00 AM.*

Thirty minutes later he came out fully dressed, and nicely so, wearing tan slacks, his chocolate brown corduroy sport coat, a yellow Oxford button-down shirt, and a tan and white striped tie. Then he noticed that I was wearing a tee shirt with a wolf on it.

*Damn, I forgot.*

“Kitty,” he said, walking toward me and nearly tripping on the edge of the living room Kilim, “I *told* you not to wear shirts with wolves on them!”

His anger was palpable.

“They’re frightening. What’s wrong with your memory?”

*As though his memory were better than mine.*

“Go home and change r-r-right now.”

“Ed, there isn’t time,” I said. “We’ll be late for your appointment.”

“Go home anyway. I don’t care ‘eef we’re late. I’m not going anywhere with you dressed like that,” he yelled.

His outrage was way out of proportion to my transgression.

“There isn’t time,” I insisted, pointing to my watch. “I tell you what. I won’t do it again. Okay?”

“Okay,” he said. “But be sure.”

We returned to the kitchen and he began his highly ritualized process of putting away the groceries. I placed the bags on the counter atop the stacks of several recent editions of the *New York Times*, and then he started putting the items away, but not before first checking off each one on the cash register tape.

“Ed, hurry up,” I said, annoyed at his time-consuming habit.

"Leave me alone," he shouted, bending down awkwardly to put a bottle of Dawn in a baseboard cabinet. "I'm almost finished."

*We'll never make it on time.*

Then he opened the bag with the bananas in it.

"What are these?" he asked, holding them at arm's length, as though they might be dangerous.

"Bananas."

"Bananas?" he asked, looking confused.

"You know – bananas. You put them on your cereal."

His face remained blank. His bewilderment scared me, but I thought it was just a moment of temporary confusion. It didn't occur to me that it could be a sign of something far more serious.

Finally we were ready to leave when I inadvertently committed another offence. It was an extremely cold snowy day and I'd worn my camel's hair coat. Without thinking I put it on *'the wrong way.'* I held it in front of me with the front of the coat facing forward, one hand on each side of the collar, twirled it up over my head and behind me, and then let the sleeves slide down my up stretched arms - first the left, then the right.

"Kitty," he said loudly, "I told you 'hunnerd' times not that way to put on your coat. You look r-r-ridiculous. You should r-r-really be more r-r-refined."

I knew if we fought over it he might get so infuriated he'd throw me out and refuse to go to the doctor at all. Although Ed no longer cared about his appearance, he had become adamant about mine. He had always encouraged me to dress nicely, had helped refine my sense of style and had been incredibly generous in buying me beautiful clothes over the years. But by then he had begun dictating how I dressed. There were many rules. Sweats were forbidden, as were shorts. Although tennis shoes and jeans were sometimes allowed, they could become the objects of ridicule. Then there was this coat issue. He was unyielding about it. So after a dramatic sigh I took my coat off and put it on again, starting by holding it low behind me, then pulling up first the left sleeve, then the right.

As we were leaving he had one of his typical sneezing fits. Eight times in a row. Then just as we were going out the door he brought up a sensitive issue for me – my weight. Over the years I had steadily gained, ballooning from 110 when I first met Ed to 185. At 5' 4", I was a good sixty-five pounds overweight, and since most of the excess weight was

around my stomach I looked pregnant. Even at my age (I was 53 at that time), I'd had people ask me when my baby was due, which was immensely embarrassing. Ed had been on me about it for years, and brought it up with just one sentence.

"Kitty," he asked, "*when* are you going to lose some weight?"

*And the day had just begun.*

### **I'm not with Him**

During the short drive to the Medical Arts Building – the MAB as we called it – Ed calmed down and behaved as though nothing had happened between us. It was snowing heavily and the wind made the car sway at times. I was lost in thought about how different Ed had been in our early years together. How he used to praise and compliment me all the time instead of berate and criticize me. He always thought I was a genius for having a thorough knowledge of music theory, especially that of the Greek and medieval periods. He was self-effacing when he talked about it, and said he'd *never* be able to learn anything as complex as that. He was impressed that I'd published a critical and performing edition of a sacred cantata by Sammartini from handwritten manuscripts I'd discovered in libraries in Munich and 'Sveet-zair-lawnd.' When I'd explained to him the meticulous process for preparing such editions he'd looked at me in awe.

I remembered arriving at Ed's apartment early one morning when his dearest childhood friend was visiting from Romania. The man was an intellectual, and at that time was the president of some or other highly - regarded American-Romanian society. He was in the U. S. for its annual meeting in New York and Ed, generous as ever with friends, had bought him a ticket to come to Cincinnati for a five-day visit. When I walked in, there was John – yes, his parents had given him that English name – in his bathrobe and slippers, sitting at Ed's little kitchen table in his outmoded oversized horn-rimmed glasses, a cup of Turkish coffee in front of him, dutifully reading my historical introduction to the Sammartini edition. Ed was so very proud of it that he'd actually made John sit down and read it. Ed was sitting, also in sleeping attire and with tousled hair, on the other side of the little table with his own cup of coffee. I assumed he was waiting patiently for John to finish reading and give his esteemed opinion of my work. I felt honored, but at the same

time sorry for John. The introduction was quite long and part of it was rather technical. It couldn't have been of any real interest to him.

Ed routinely sang my praises to others whenever there was the slightest opportunity to fit it into any discussion. In addition to praising my abilities as a musicologist, he was forever talking about my tremendous success as a grant writer at the University of Cincinnati Department of Family Medicine. He couldn't resist telling others that my grants had brought in millions of dollars over the years. Ed's incessant praise of me, while completely earnest in his mind, was rather inappropriate. My intellect wasn't anything extraordinary. *He* was the one who was brilliant.

Ed was a true Renaissance man, as were many Europeans of his generation, but he stood out among them because his memory was phenomenal. It was his most distinguishing feature. He'd remember everything he read, heard or saw. It was that simple. We typically refer to such people as 'walking encyclopedias,' but Ed was more. Far more. Ed was a walking library.

Many times when my friends and I had academic discussions we'd get stumped by some question or other. I'd always say, "Let's call Ed. *He'll* know." And he did. Every time. I was ever so proud that my Ed could delve into that stunning memory and within seconds retrieve the answers to our sometimes ridiculously obscure questions. He would eagerly shout them out as though he were on a TV game show when the first contestant to answer correctly won.

Ed was a cosmopolitan, too. He knew so many languages. In addition to his native language, he spoke English, French, and German fluently, and he read Italian, Latin, and Russian. Most highly-educated people know multiple languages, of course, and Ed was no exception. What was nearly unbelievable, however, was that even when he became seriously demented he could still speak English, French, and German. He couldn't remember if he had lunch, he didn't always know if it was day or night, he couldn't tie his shoes, couldn't talk on the phone, but he could easily converse in those languages.

Ed had received a classic European education in Bucharest and subsequently earned a law degree there. He became a tenacious defense attorney, racking up an astounding number of acquittals for his clients. Then he changed his professional focus to literature and philosophy, and studied further in France and the U. S. He had read nearly all of the



approximately 1,200 books in his personal library - "Plus," as he once said to a friend admiring his collection, "a *few* more." The "*few* more" were in fact 'hunnerds' more if not 'tousands' more.

His 1973 doctorate from the University of Cincinnati was in Romance Languages and Literature, which required a thorough knowledge not only of literature, but also comparative literature, literary theory, literary criticism and other related areas. It seemed that when I arrived to visit he was always hunched over his kitchen table smoking a cigarette while deeply immersed in a thick book in one language or another about those very topics.

And if he wasn't studying those issues he could usually be found pouring over one of his numerous books about philosophy, most of which were in German. Philosophy was actually his first love. He was obsessed with it. Reading those arcane books brought him great pleasure, but also appeared to be an awesome duty – almost a moral obligation. Those books, like the newspaper, *had* to be read every day. Suffice it to say there was no dust on his philosophy books.

His knowledge and scholarly interests didn't stop with literature and philosophy, however. He was incredibly well versed in many other areas as well, including music, art, architecture, history, and – most of all – current world events. He'd routinely tell me about events - even those of little interest or none at all – that had happened that morning in some tiny country I couldn't even find on a map.

Though Ed's unshakable memory and vast fund of knowledge were amazing, his brain was far more than a mere repository for facts and figures. He could *do things* with the knowledge he possessed. He could analyze complex philosophical issues. Discern subtle differences between quite similar works of art. He could debate controversial literary theories. Distinguish between the core of an issue and the fluff. Synthesize voluminous amounts of information and get to the bottom of it, distilling it to what was truly significant.

Even more surprisingly, for a proud man – and Ed was indeed a proud man – he was humble before the scholars he'd met along the way whom he considered more knowledgeable and capable than he. He especially admired Mircea Eliade and Jacques Derrida. He told me that he had 'but a poor mind' compared to them. He attended lectures by each and talked about them for days afterward. With awe in his voice, he told me how fascinating, challenging and illuminating they had been. From the

way he talked you'd have thought he'd been to hear orations by Plato himself.

But all that would fade into darkness when Alzheimer's overtook him. I was grateful at least that he didn't suffer. As it turned out he never knew he'd lost anything.

As we got closer to the MAB for Ed's appointment with Dr. Bibler that morning, I realized Ed was 'meex-ed up' and thought he was going to see another doctor, Dr. Bracken, about his prostate. I told him he was seeing Dr. 'Bee-bler' for his allergies. He seemed to understand, but I didn't know how long he'd remember.

"Go sign in, Ed," I said, when we got to the waiting room.

I sat down on one of the few available chairs, which was far more uncomfortable than it looked, while he walked to the Plexiglas-covered receptionist's window, sneezing four times on the way. He picked up the pen and started to write his name, but then, without warning, he shouted, "I will *not* sign my name here!"

His voice drew everyone's attention. People looked up from their cell phones and worn magazines and stared at him. Some looked shocked, especially an elderly silver-haired gentleman in a dark blue suit who peered up over his dark-rimmed glasses. Others just appeared to be curious.

"You have to sign in," the receptionist said, "so we know you're here and what time you arrived." She said it curtly, apparently sure it would convince him to sign.

I knew better.

"No! I r-r-refuse. You *know* I'm here," he insisted. "I am *not* signing my name here like a schoolboy."

*Oh, God! Not this again.*

I gritted my teeth and closed my eyes. He'd done the same thing at the dentist's office the previous week.

He came back and sat down beside me. Embarrassed, I immediately moved one seat over, picked up a ten-month old issue of *Time*, and pretended I wasn't with him. He then moved to the chair I'd just vacated, so we were sitting adjacent to one another again. I ignored him and kept staring at the dumb magazine, hoping people would think we weren't together.

Dr. Bibler was obviously running late. Very late. The minutes ticked by ever so slowly.

"I've been here waiting twenty-five minutes," Ed said a few minutes later, stomping back to the receptionist's window. "How much longer do you r-r-really think I'm going to wait?"

I wanted to just get up and go home, leaving him there all by himself.

"It will be just a few more minutes, Dr. Theodore," the receptionist said firmly.

Her name was Mary. She was very young and couldn't pronounce his last name properly, but she'd known him long enough to know he wanted to be addressed as 'Dr.' Theodore. Ed was obsessed with the fact that we both had PhDs, and he never missed an opportunity to refer to me as "Dr. Marie Marley" or introduce himself as "Dr. Edward Theodoru." Frankly, I was embarrassed by this. There was no reason to introduce me as "Dr. Marley" to the paperboy or the cabdriver. When writing his name on a form or something, he always put "Dr. Edward Theodoru," instead of "Edward Theodoru, PhD." Although the former was correct, of course, it sometimes made people think he was a medical doctor, and I honestly believe that's what he wanted. When he'd call CVS to refill a prescription, he'd follow the instructions on the recording with precision: "Press one if you're a patient. Press two if you're a doctor." He always pressed two.

He walked back and sat down in the chair next to me.

"Always here they are late!" he told me.

There was no way I could keep pretending I didn't know him. He was sitting right beside me and was obviously talking to me.

When the nurse finally came out and called his name, he got up and disappeared with her behind the door leading to the exam rooms.

I sighed, resigned to the fact he wasn't going to understand half of what Dr. Bibler was about to tell him and wouldn't remember much of what he did understand.

*Thank God this visit isn't about a life-threatening condition.*

Ed returned ten minutes later, a little white sheet of paper fluttering in his trembling hand. We filled the prescription without incident at the first-floor pharmacy. I hoped the rest of the day would go better.

"Let's go for lunch at Lenhardt's," he said when we got settled in the car.

All I wanted was to get away from him and have a little peace and quiet.

“Ed, I would love to, but I don’t have time,” I said, fastening my seat belt. “I’m working on a major federal grant. It’s due Friday.”

“You have time for lunch,” he said matter-of-factly as I helped him with his seat belt. He was no longer capable of fastening it by himself.

“No, I don’t. I have to go home and work,” I said, putting the car in reverse.

I often worked from home. After the scene he’d made at the doctor’s office I had no intention of having lunch with him that day. I was sure he’d just make another scene right there at the restaurant. He’d been doing that often those days.

### **First Date**

I couldn’t help but think of how gallant and chivalrous he’d been at our first dinner at the Edgecliff back in 1975. I remembered how he’d kissed my hand when I opened the door of my apartment to greet him. That gesture and his smile had felt slightly seductive that night. And that even though he had tricked me into the date.

He’d tricked me indeed. A few months after Guido had introduced me to him, the phone had jarred me awake from a much-needed and pleasant Saturday afternoon nap. I’d delayed a moment to light a cigarette, then lifted the receiver.

Exhaling the smoke, I answered.

“Hello.”

“Is this Ma-r-r-ie?” asked the heavily-accented bass voice.

“Yes, it is.”

“Here is Edward Theodoru,” the booming voice at the other end said.

I was thoroughly confused. I couldn’t imagine any reason for Ed to be calling me. At first I was terrified that something bad had happened to Guido and Ed was calling to tell me the news.

“Would you have with me ‘dee-ner’ this evening?” he asked.

That confused me even more. He *knew* I was deeply in love with Guido, his *friend and colleague*. I couldn’t believe he had the audacity to make a play for me. So I just took a drag from my cigarette, not yet fully awake and too confused to respond.

“Ask to come with you a girlfriend,” Ed suggested, evidently noting my indecision.

Well, that changed everything. I exhaled in relief and crushed out my cigarette. If I could bring a friend, then he obviously wasn’t asking me on a

date. He probably just wanted some company for 'dee-ner'. So I accepted and – *just as I'm sure he had hoped* – I didn't bother asking a girlfriend to come along. That's how naïve I really was. But truth be told, although I was passionately in love with Guido, who was away on his annual summer trip to Italy, I secretly found Ed enchanting and felt a tinge of excitement at the prospect of having 'dee-ner' with him alone.

That evening I was decked out in an unusually gaudy dress in a tacky shade of turquoise, cut too short, nearly transparent and showing entirely too much cleavage. Having an atrocious sense of taste in those days, I innocently thought I was dressed splendidly. He was probably aghast, perhaps even a bit embarrassed to be seen with me, but then again, I *was* young and pretty. A little on the short side at 5'4", my body was nonetheless well proportioned, although at 110 pounds I was almost a little underweight. My long brown hair, which I often wore in a ponytail, drew attention to my dark brown eyes, which my mother always lovingly referred to as "big and beautiful."

Ed, on the other hand, was well dressed in a navy blazer, tan dress slacks, and a pale yellow shirt embellished with a tasteful burgundy- and grey-striped tie. He had a distinctly triangular-shaped face and aquiline nose. Combined with his black hair, chocolate-colored eyes and bronze complexion, he was truly tall, dark and handsome.

I was 25 and decidedly immature for my age. I didn't know how old he was. Certainly old enough to be my father, but then so was Guido, so I didn't really think much about it. Besides, this wasn't a date as far as I knew, so our relative ages didn't matter. I wouldn't have bothered asking anyway because I'd learned that when older men spent time with young girls they usually lied about their ages.

He lived at the Edgecliff apartment building, which just happened to have a restaurant, and he just happened to suggest we go there for 'dee-ner.' In my youthful innocence I never saw it coming.

The restaurant had a striking view of the Ohio River, and Ed requested a table next to one of the large windows. When we reached the table, covered with a starched white tablecloth and bearing a little vase of fresh daisies, he pulled out my chair for me.

*Gee, no man ever did that for me before.*

Soon after, a rather young-looking ultra-skinny teenaged waiter wearing a black shirt and very tight black pants brought us ice water with lemon slices on the rims.

"The service is usually r-r-really quite slow here, so we will have for conversation a lot of time," Ed smiled.

Just as I was unfolding my napkin he motioned for the waiter.

When the young man arrived, Ed calmly announced, "We'll move to that table there," and he pointed to a table on the other side of the room, also by a window.

I have to admit I was perplexed as to why he wanted to move, and I felt somewhat embarrassed as we picked up our silverware and napkins and traipsed to the new table following the waiter, who was carrying our water glasses. I thought about asking why he wanted to move, but decided to let it go. He held out my chair for me as he had at the first table. Once we were re-situated, the waiter took our orders. I ordered broiled pork chops; he, baked halibut. I also ordered a salad, but he didn't want one.

"It is just grass," he said.

I started the conversation off awkwardly by asking him a most predictable question.

"What did you write your dissertation about?"

I put my napkin on my lap again.

"J. G. Sulzer and his contributions to the French Encyclopedia."

"Who was J. G. Sulzer?"

"He was an 18<sup>th</sup>-century Swiss aesthetician."

I didn't know what an aesthetician was, but didn't want to appear ignorant so I didn't ask. I got a Salem from the pack I'd placed on the table and was pleasantly surprised when he produced a lit match just at the instant I put the cigarette to my mouth.

*What a gentleman.*

"Swiss, huh?" I asked, inhaling. "What language did he write in?"

"German."

"German? So you know Romanian, English, French, *and* German?" I said.

I only knew English, of course, and Italian, but would need to learn to read German and French for my doctorate.

"Yes. And I can read Italian and R-r-russian," he said with gusto. "And a 'lee-tle' Greek."

As that was sinking in, the waiter brought my salad and some warm French bread wrapped in a linen napkin placed in a little wicker basket. The

bread's aroma made my mouth water. Bread was one of my greatest weaknesses.

"What is your specialty?" he asked.

"My bachelor's degree is in performance."

"Oh! What do you play?"

"I play the clarinet. In fact, I won a performance competition for a four-year full-tuition scholarship to UC – that's the only way I could have afforded to go to college – but later I changed my major to musicology."

"I *thought* Guido told me you were a musicology student. What did you do for your master's thesis?" he asked as I took a sip of my ice water, hoping I was doing it daintily.

"I studied a group of sixteenth-century Italian madrigals set to sonnets by Petrarch."

"Madrigals set to Petrarch's sonnets. What an interesting topic!" he said. "I recall there was a r-r-resurgence of interest in Petrarch's sonnets among the sixteenth-century 'Ee-talian' madrigalists."

I sat there with my mouth hanging open, amazed that he knew this bit of information. Many musicologists wouldn't even know it unless they'd specialized in Italian Renaissance music.

*This man is brilliant.*

And not only did he *say* my thesis topic was interesting, he truly *seemed* interested in it. And what he asked next really pleased me.

"Ma-r-r-ie, would you let me sometime r-r-read your thesis?"

"Of course," I said, beginning to really enjoy this 'dee-ner.' It never occurred to me that he might be flattering me as a means of seduction.

Then he changed the subject and, lighting a cigarette for himself, stated proudly, "I don't want to brag but I was a r-r-really successful defense attorney in R-r-romania before I came here in the '60s." He had a broad grin on his face. "I love to argue and almost always I win."

I would later learn that, unfortunately, he really did love to argue. In fact it was one of his hallmark traits.

"Tell me about one of your interesting cases," I said, partly because I thought that was the polite thing to ask and partly because I was curious.

"Well, let me see," he said, tilting his head back and slightly to the left as though trying to recall some ancient memory.

While I was waiting for him to decide on a story, I picked up a piece of bread and buttered it, which was difficult because the pat of butter was very cold – almost frozen.

“Once I defended a young man accused of r-r-aping a ‘veer-gin,’” he began. “The beautiful girl’s testimony sounded convincing, and things were looking pretty grim for my client. But I was convinced of his innocence, so I decided to play detective. I went to the small town where the accuser ‘leev-ed’ previously and did some legal r-r-research. After hours of tiresome review of stacks of public documents, I discovered that this same girl had brought an *identical* lawsuit there. So my client was immediately acquitted and the prosecutor brought charges against his accuser.”

As he ended his story he took a slice of bread and began working to smooth the cold butter onto it. He looked as annoyed as I’d been.

“Wow! That’s impressive! Why did you become a French professor here instead of a lawyer?”

“I realized I’d never well enough master the English language – plus I have a heavy accent.”

That was an understatement, to say the least. But to me his accent was so charming.

“I doubt I’d have been in this country a successful defense attorney,” he continued, “and that’s the only kind of lawyer I’d ever want to be. I couldn’t stand to be a corporate lawyer – sitting at a desk ‘feel-ing’ out forms all day. So I just decided to become a French professor. I knew it would be relatively easy since I already knew the language.”

I was really hungry by then. The waiter was headed in our general direction, but as he neared I could see he was carrying some other diners’ food.

“How did you learn to speak French so well?”

“I learned it as a child. When I grew up in R-r-romania all the middle class people knew French and, in fact, many spoke French at home. How about you? How did you learn ‘Ee-talian’?” he asked.

“I taught myself. When I was in high school I loved Italian opera and followed along with the translated libretto when I listened. But I always felt I was missing something in the translation so I just decided to learn the language. I studied a textbook and then I found an Italian family that let me practice speaking Italian with them. Then when I got here I took Italian classes for three years.”

I took another cigarette out of the pack, which he lit as quickly and chivalrously as he’d lit the first. I smiled.

“Tell me another story.”



I said it as innocently and eagerly as a child asks her father to tell her another bedtime story. I propped my elbows on the table and clasped my hands under my chin. I was enjoying myself.

“Okay,” he said, pausing as if to think which of the many stories he had lived he wanted to tell me about next. “Oh, I know – I’ll tell you the ‘Jeep-sie’ story.”

Sounded like it was going to be a good one.

“Once I represented a group of ‘Jeep-sies’ in R-r-romania. A little band of them, very filthy and loud, came to my tiny waiting room one day making quite a bit of noise. I made them come immediately into my office because they were disturbing the other lawyers in the building. They presented their complaint: the government had confiscated all of their gold coins.”

He leaned forward, looked around to see if anyone was listening, then lowered his voice and whispered, “The damned communist r-r-regime didn’t allow *any* citizens to possess gold, but my family had some hidden.”

I didn’t know at the time that he’d come to this country as a political refugee or that at one point the Romanian secret police had been looking for him.

“They begged me to take their case,” he continued, sitting back in his chair and resuming his normal tone of voice. “I finally told them I would do it under one condition. They had to promise they would *never* come back to my office again. I said I’d meet with them at a nearby park. To make a long story short, I eventually did get their coins back through a loophole I discovered in the law. They were overjoyed, rewarded me generously, and invited me to a big celebration they were going to have at their camp way outside the city that night.”

“Did you go?” I asked.

“No, of course not. I politely declined.”

“Yeah. I can’t see you going to such a thing. By the way, I had an odd experience with a Gypsy when I lived in Italy.”

“When did *you* ‘leev’ in ‘Ee-taly’?”

“During my senior year in college. UC has an exchange program with the University of Pavia. Guido convinced the Italian teacher here in charge of the program to select me to go one year.”

*We sure were making a lot of references to Guido.*

“What did you study?”

"I studied the operas of Monteverdi with a well-known Italian musicologist named Rafaello Monterosso –

"That's an interesting combination of surnames."

"Yes. I know. Green and red mountains. Anyway, I also studied clarinet with Orlando Ianelli, who was the second clarinetist in the La Scala Opera Orchestra."

"R-r-really?"

"Yep!"

"You studied with a La Scala Opera Orchestra clarinetist?" he asked, squeezing some lemon into his ice water and inadvertently squirting me in the face.

I dried my face with my napkin, which made him realize what he'd done.

"Oh! I am so sorry, Ma-r-r-ie. Excuse me, please."

"That's okay."

Then I answered his question.

"Yes. I really did study with a La Scala Opera Orchestra clarinetist."

"Seriously?"

"Yes, sir. I took the train to Milano once a week, which was like thirty miles from Pavia. In fact, the year I was in Italy they had an opening for the third clarinet position and my teacher wanted me to audition for it."

"*Did* you?" He raised his voice and sounded excited so I knew my answer was going to disappoint him.

"No," I said, firmly putting out my cigarette in the tiny glass ashtray.

"Ma-r-r-rie! Why not? You mean you actually passed up a chance in the La Scala Opera Orchestra to be?"

"Well, I didn't think I'd have any chance of winning the audition. And if I did, I'd have been petrified. Imagine the pressure. It was *La Scala* for God's sake. Anyway, I wanted to come home after my year was over. I missed Guido terribly."

*And there he was again – Guido.*

"Speaking of opera," I asked, as the waiter approached our table only to veer off in the other direction again, "do you like it?"

"What – opera? No. I *hate* it. I can't stand seeing the singers on stage with 'the mouth' open wide."

He made an exaggerated facial expression, grossly mimicking an opera singer hitting a really high note. I wondered how he expected singers to emit sound if not with 'the mouth' open.

“But a funny thing happened one night when I was at the opera in Bucharest,” he said. “They were performing R-r-rigoletto and I was bored to death so I decided to leave. I very slowly walked to the door and discretely opened it.” Then he laughed. “Only thing was,” he said, “it was the door to a closet. So there I was in front of all those people standing in a closet with a mop and a broom!”

We both laughed and simultaneously reached into the little basket for another slice of bread. Our hands almost touched.

The waiter arrived and put down our plates. I’d been so engrossed in our conversation I hadn’t even touched my ‘grass.’

“You can take the salad,” I said.

The moment the waiter was out of earshot, Ed casually asked me in his deep bass voice, “Speaking of ‘Ee-taly’, would you like to go there on a vacation with me sometime?”

I was shocked by his brazenness. I guessed I’d been wrong about his intentions for this ‘dee-ner.’ It was a date after all. I rested my cigarette in the ashtray and, as the smoke curled up toward the ceiling, just stared at him. I had no idea what to say. My eyes turned toward the window and I gazed at the magnificent Ohio River and the Northern Kentucky shore as I tried to think of an answer.

Finally one came to me.

“I’ll have to think about it,” I said.

We continued with more pleasant conversation, but that startling precipitous question stayed in my mind for an incredibly long time.

### **Lunch at Lenhardt’s**

I was abruptly jolted back to the present when a driver cut me off right in front of Lenhardt’s. I slammed on the brakes to avoid hitting him. Cursing out loud, I turned into the parking lot and found a spot all the way in the back. Ed had talked me into lunch after all, and when we entered the restaurant, the aroma of the Hungarian food was so tantalizing I could almost taste it. We hung up our coats, whitened with snow just from the short walk from the parking lot, and the elderly owner’s wife escorted us towards a table in the main room.

“No,” Ed said. “We will in the other r-r-room sit.”

He pointed to the room on the right.

His tone of voice had been polite enough, but I wished he'd said something like, "May we please sit in that room?" But that would have been asking too much those days.

She changed course and we followed. She seated us near a young couple with a child who was pounding his spoon on the table. I didn't think that seating arrangement was going to work. He never wanted to sit near children. Sure enough, after we'd been there five minutes, he motioned for the waitress. I knew what was coming.

"We want to move *there*," he said loudly, pointing to a table on the other side of the room. "The child is too loud."

I was embarrassed for the child's parents – who certainly heard Ed – and for myself, as we got up and walked to the new table. Shortly thereafter, the hostess brought us some ice water. She was a sixtyish pleasantly plump, well-coifed blond. We went there often enough to know that she was from Hungary and spoke Romanian rather fluently. I loved her charming accent and mannerisms.

I wanted to kid Ed sometime and call him a jerk in Romanian, so I asked her, "How do you say 'jerk' in Romanian?"

She answered almost instantly, dramatically flinging her right arm high into the air, "There *are* no jerks in R-r-romania!"

Soon she brought us bread and pats of butter wrapped in gold foil paper, and a little later the waitress came to take our orders. A brunette in her mid-forties, this particular waitress, Jenny, had been serving us for years. Short and a tad overweight, she was wearing her required uniform of black slacks, a white blouse, and a white apron. Jenny was consistently pleasant and put up with the rudeness Ed had been displaying in recent times. I was grateful and admired her for it.

We both ordered Wiener schnitzel, their specialty. It's what we always ordered. A few moments later, Ed – and I'd been afraid he'd do this – decided he didn't like *that* table either.

He motioned for Jenny and when she arrived he said quite loudly in an angry tone of voice, "This table is *drafty*. We'll move over there."

I was embarrassed again, but not surprised. He'd been doing this 'triple-table-changing routine' for years and I was used to it. So was she. We picked up our silverware and napkins; she took our water glasses; and the three of us paraded to the new table.

Once ensconced, we started talking about my sister, who was coming down from Toledo to visit for a long weekend at the end of the month.

Fredrica, whom we called Freddie, was 46, five years younger than I, and had met Ed on several occasions when she'd come to visit me. She called him 'Mr. Ed,' based on the TV show that ran in the early '60s when we were kids. Since he wasn't in the U. S. when that show was on, he didn't know she was good-naturedly calling him by the name of a talking horse. I don't think she understood why I was involved with someone as old as Ed, but she liked him and was taken by his chivalrous manners and charming accent. He liked her, too. He liked *all* pretty young women, and she was very pretty.

Freddie and I enjoyed our visits tremendously. Sometimes we laughed ourselves silly over little nothings. We didn't have much in common, yet we always had tons of fun, and I was looking forward to seeing her.

Jenny arrived with our food and put it down on the table. The schnitzel smelled incredibly good, and steam was rising from the mashed potatoes. I hoped the meal would proceed without further disruption, but I wasn't counting on it.

"You've never told me anything about your brother," Ed said, as we started eating. "Why doesn't he ever come visit like Freddie does?"

"I don't want him to come and visit," I said with no hesitation whatsoever.

At 55, Phillip was four years older than I. We grew up fighting constantly and hating each other, which my father encouraged. Once we left home we didn't keep in touch until we were much older and circumstances *forced* us to communicate. But when we were younger we didn't visit. Didn't write. Didn't call. Not even at Christmas or for birthdays. We only knew about each other's lives what our parents told us in our weekly phone calls with them.

"I'll tell you about him some other time," I said.

Thinking of all the fights I'd had with my brother reminded me of the first argument Ed and I had. It was back when we were lovers in 1976. I was 26 and Ed had just turned 63. We'd been together about a year. One evening we were driving to the university. He was going to teach his Evening College French class and I was going to the College Conservatory of Music (CCM) library to continue my dissertation research on Sammartini. It was a rainy evening and strong winds were strewing leaves all around the campus streets and lawns in big wet clumps. So many landed on our windshield that the wipers got clogged with them, and the leaf-laden blades were swinging back and forth

making loud thumping noises. Ed was talking about Jimmy Carter's recent election.

He hated Carter and was berating him endlessly.

"I don't really care about politics that much," I finally said because I was getting tired of hearing Ed say the same angry things over and over. I was shocked when this heretofore mild-mannered gentleman started yelling.

"You *should the hell* care about politics, Kitty!"

I cringed and stinging tears flooded my eyes.

"Why are you crying?" he asked in a normal tone of voice, sounding genuinely perplexed.

"Because you're mad at me," I sobbed, getting a Kleenex out of my purse and dabbing my eyes.

"I'm not mad at you," he said calmly, reaching over and resting his hand on my knee. "What makes you think I'm mad? I'm just telling you what I *think*," he said, as though that would explain why he'd yelled.

And so it was. I soon learned that when Ed yelled it didn't *necessarily* mean he was angry. Sometimes he just got carried away and raised his voice while expressing himself. This was one more of his signature attributes. I thought it was strange, but finally did get used to it and labeled it 'just being Ed.'

Eventually when we talked and he started yelling, I just yelled back – neither of us actually angry, just expressing ourselves 'Ed-style.' He was the only person in my life I routinely yelled at. More importantly, he was the only person I ever allowed to yell *at me*. Unfortunately, those around us didn't understand our way of communicating and thought we fought a lot.

We did have some *real* fights, too, of course. Usually about twice a year. And they were good ones. Yelling, cursing, slamming fists on tables – that sort of thing. But when it was over it was *over*. After a few minutes we'd pick up and go on affectionately, saying "Kitty this" and "Kitty that," as if nothing unpleasant had happened between us. In a way it was almost funny. Only much later would our arguments have far worse consequences.

"How's your mother? Have you talked to her lately?" Ed asked, interrupting my thoughts and bringing me back to the present.

"Oh, she's fine," I said. "I talked to her Sunday. I talk to her every Sunday."

When my father had died of a stroke a few years earlier, my mother couldn't take care of herself anymore. She'd lived with my brother and his wife for about six months but after that he put her in a nursing home. She'd made a lot of friends there and was getting along very well.

"She gets coffee for the residents who can't walk to get their own. She's been doing that for awhile now, and so the management is going to give her a volunteer badge. She is thrilled about that. She also told me the nurse practitioner there said she's 'a ray of sunshine in a dark place!'"

Just then Jenny brought our check. Ed got his Visa card out of the disintegrating wallet I'd given him fifteen years earlier. He refused to replace it, saying he was emotionally attached to it. He tallied the numbers in his head but got confused so he passed the little slip to me. I never checked my restaurant bills. I just paid. But I humored him, added up the numbers and told him it was correct: \$19.96. I figured the tip should be three dollars plus another dollar just for putting up with him.

"Leave four dollars," I told him.

"Four dollars?" he blurted out. "That's too much. What did she do that was so special she deserves *four* dollars?"

His voice was so loud that not only could everyone in the room hear him, I was sure that Jenny, who was just outside in the hallway, could hear him, too.

"Ed," I said calmly, "just leave the tip and let's go."

"No. I will *not* leave four dollars, Kitty. She doesn't deserve it," he said loudly.

He'd made scenes like this in restaurants twice in the previous six months and this time something in me snapped. It was one thing if he yelled at me in private. But it was another if he embarrassed me like this in public. I vowed right then and there that I would never ever take him to a restaurant again.

And I never did.

Surprisingly, he never asked me why we weren't going to restaurants anymore, and he never asked me to take him. He just seemed to forget that restaurants existed.

I was still in denial, of course. It still didn't occur to me that Ed might have dementia, which could be causing him to behave so badly. I just hoped we could get through the rest of the day with no more outbursts from him.

### Choosing a Lover

On the way back to the Edgecliff Ed quieted down, as he had on the way to the MAB earlier that morning after our fight at his apartment. He remarked how beautiful the trees were with their snow-covered limbs, but that he worried about driving conditions even though I was the one driving. I was sad about my resolve never to go out to eat with him again, but I knew it was the right decision. Things simply had changed too much since our first dinner at the Edgecliff.

Thinking about that first dinner never fails to bring a smile to my face. In retrospect, I can't believe how naïve I was then. As anyone but I would have predicted, after dinner he invited me upstairs to his apartment. I don't recall if it was to see his etchings or if he offered some other enticement, but I went.

His one bedroom apartment on the ninth floor was nicely decorated with Kilim area rugs. The living room walls bore a mixture of modern prints and original artwork. The former included Klee's *Blaue Nacht*, which now hangs on the wall across from my desk. The latter included, among others, two works by a Romanian artist who was a distant relative of his. The furniture was a fitting combination of contemporary and older styles.

The room had glass doors leading to an intimate balcony, where we went to smoke and enjoy the gorgeous view of the river. We saw not only the river, filled with little pleasure boats flitting around, but also the colorful Northern Kentucky shore, replete with anchored restaurant boats and their requisite parking lots.

It was a little chilly, and so we went back in. As soon as I sat down, Ed offered me a drink, but all he had on hand was Scotch. I hated Scotch and declined twice, yet he stubbornly insisted. I finally gave in and drank a little. It burned my throat as I swallowed, and I was beginning to feel somewhat uncomfortable. But what he did next downright floored me. After lighting a cigarette, Ed walked over to one of the many bookcases standing guard along the perimeter of the room, picked up a well-worn copy of Henry Miller's *Tropic of Cancer* – pages yellowed; spine creased – sat down across from me in his recliner, opened the book to where there was a bookmark, and started reading aloud. What he read were some rather 'titillating' passages.



I took a cigarette for myself, which, of course, he reached over and lit immediately, and sat stiffly on the sofa, hoping he wasn't going to approach me sexually. I had a policy about not sleeping with men on the first date. Although Ed was always distinctly eccentric, I would later learn that his behavior that evening was unusual even for him.

Oddities aside, I honestly don't remember how that evening ended, and that's the truth. If we had sex it wasn't memorable. What I *do* remember is that after that first date he pursued me in the usual ways, adding, of course, his most chivalrous European touches.

Throughout July, while Guido was living it up in Italy, Ed and I saw each other more and more often. Three weeks into our relationship I began staying overnight at the Edgecliff, sleeping with Ed in his cozy twin bed. At the beginning of August I just moved in. All the while I was wondering what on earth I was going to do when Guido returned at the end of the month. I finally decided to enjoy myself and worry about Guido when the time came.

And the time *did* come. Guido returned from Italy at the end of August, and was excitedly anticipating our first get-together. He was badly shaken when he found out where I was and what I was doing. After the initial shock, he decided to put up a fight to win me back. A monumental tug-of-war ensued. The more Guido pulled me toward him, the more Ed pulled me back. Each bought me presents such as clothes and jewelry, sent me flowers and candy, and took me to expensive restaurants. But mostly, each professed his love for me, told me that he loved me more than the other did, and elaborated on what he could offer me that the other couldn't. Although all the attention was nice in a way, it didn't feel good for very long. I was torn between my two Latin lovers, and the three of us approached emotional exhaustion. I tossed and turned every night, reviewing my feelings for them, weighing the advantages and disadvantages of each.

Guido was a cute 5'2" small but perfectly proportioned man, who, because of his size, had to have all his clothes tailor-made. He was a passionate and expert lover both emotionally and sexually. He was Italian in every way, sensitive to his core, never reluctant to cry openly about things that touched him. He was forever expressing his ardent love for me.

Ed on the other hand had a calmer disposition. A quintessential European gentleman through and through, he always opened doors for me, held out my chair in restaurants, frequently kissed my hand, and never missed an opportunity to send me flowers or deliver flattering remarks. He

was less melodramatic in conveying his feelings for me, but he treated me like a cherished treasure and made it clear that he loved me and wanted to be with me. While Guido seemed to love me more *passionately*, Ed seemed to care about me more *deeply*.

The whole month of September went by as I anguished over my decision. My love for Guido was passionate, whereas my feelings for Ed seemed more like affection than love. But the thing was, I was enjoying myself so much more with Ed than I ever had with Guido.

I made several false starts. First I chose Ed, of course, because he was the one I was living with. But then after a beautiful afternoon with Guido I changed my mind. We had a long talk during which he kept calling me his 'beloved,' telling me he loved me more than life itself. He said no one, not even Ed, could possibly love me so much. After our talk we had spectacular sex, followed by more professions of love. He cried and asked me to come back to him.

I did.

When I told Ed I was going back to Guido he said he accepted my decision but asked me to have just one more 'dee-ner' with him for sentimental reasons.

I agreed.

I thought it was only fair. He was so gallant and chivalrous that evening that I was once more taken by his endearing charm and sincere expressions of love. By the time the evening was over I had changed my mind once again.

I spent the night with him.

This pattern kept repeating itself until the two of them got together and shook on a gentleman's agreement. They would cease all efforts to win my heart and simply let me choose. They also agreed that neither one would tell me about their conversation. The very next day Guido told me all about it. Ed, on the other hand, never said a word. I always admired him for that. I brought up the subject much later and all he said was "*Pacta sunt servanda*," which he immediately translated for me, "Agreements are to be kept." Then he added, "Cicero."

Ed was always peppering his speech with Latin sayings like that.

I finally settled down with Ed. I can't quite say why I made that decision. It just felt right. Our ever-deepening love over the years would prove I'd made the right choice.

This marked the end of my relationship with Guido, but Ed stayed in touch with him, calling from time to time just for a friendly chat. Their struggle over me was eventually forgotten. He continued calling even after Guido moved to Florida in the '80s. One evening several years later Ed received an out-of-service recording when he called Guido. Ed was distressed and started pacing the floor. I assumed that Guido, like Ed in his eighties at the time, had probably had to move to a nursing home. I was right. Early the next morning Ed sat down and called several nursing homes in and around Deltona, the small town where Guido had moved to, and finally found the nursing home where he was living.

The nurse gave him sad news. "I'm so sorry to have to tell you this," she said. "But he has advanced Alzheimer's. You wouldn't want to talk to him the shape he's in. He wouldn't know you and he can't speak coherently."

Ed was devastated, more distressed than I'd ever seen him. In the following weeks he brought up the subject frequently. He suffered deeply for his old friend and colleague.

### **The Crooked Stamp**

Pulling up under the portico at the Edgecliff after our appointment with Dr. Bibler and lunch at Lenhardt's, Ed asked me to come up and help him pay his bills. I didn't know if he really wanted help or if he just wanted me to spend more time with him. I sighed and said okay, even though I really should have gone home and worked some. But Ed's bills had to be 'payed' (as he spelled it) or they'd turn off his lights, stop delivering the paper or cut off his phone, and I'd just have to spend a lot of time straightening everything out. This was the lesser evil. And I thought maybe if I spent some more time with him we could end the day on a better note.

He brought out all his bills and put them in a stack on the dining room table. Before we started I made us Turkish coffee and put out two little plates with Linzer torte, his favorite dessert, which I bought for him every week at Servatii, one of the best pastry shops in town. Then I opened the bill on top and told him to write out a check to Cincinnati Bell for \$50.26. I was pleased, and a bit surprised, when he did it correctly on the first try. Then he put the slip of paper to be returned with the payment behind the check and stuffed them in the envelope, with the check showing through the window on the front. I told him to reverse the order of the slip and the check, and he was able to do so.

*This was going well.*

Then he got up, went to the freezer and got his Popov. He poured a water glass half full, as usual, and brought it to the table.

When he sat down again I told him to write his return address on the envelope. He looked at me as though I'd spoken to him in Chinese. He said he couldn't remember it and would I please just do it for him. I did, abbreviating Cincinnati as I always did – 'Cinti.' I felt deeply sorry for him that his mind had deteriorated so much.

What happened next caught me off guard.

With no warning he shouted at me, "What's wrong with you, Kitty? Do you abbreviate Cincinnati on *your* bills? You have to spell out what it stays for."

*He always said 'stays for' instead of 'stands for.'*

He grabbed the envelope in his shaky hands and tore it to shreds, continuing to yell at me.

"Do it over!" he said, getting a new envelope out of a box on the table and throwing it down in front of me.

I took a deep breath, and did as he asked, careful to spell out C-i-n-c-i-n-n-a-t-i.

"Good," he shouted. "Thank you. That's the r-r-right way."

Next I put on the stamp, a little too haphazardly.

Realizing that the stamp was askew, Ed lost it.

"Kitty," he hollered, putting his glass down forcefully and slamming his fist on the table. "Look what you did. It's crooked. You *r-r-ruined* a perfectly good stamp!"

"Ed," I said, struggling to control my temper and not slam down *my* fist. "It doesn't matter. The post office doesn't care if it's on *straight*. They just care that it's *on*."

"No!" he screamed, standing up and leaning over me. "You know you are *w-r-r-rong!*"

I lost it and unleashed the anger that had been building up all day.

"Ed," I yelled at the top of my lungs, hurting my vocal chords, "it doesn't *matter* how the stupid stamp is on the envelope. Do you *hear me?* It doesn't *matter!*"

"Get out!" he hollered.

"Go to Hell!" I yelled.

I put on my coat, the wrong way on purpose, and ran out, slamming the door behind me.

I was seething with anger. I was so angry my hands were shaking and I was virtually hyperventilating. I was grateful no one else was on the elevator with me. After I got in my car, I slammed its door, too. Hard. I fumed all the way home, cursing at him aloud and silently in alternation. All I could think about was how mean and hateful he had become and that I never wanted to see him or speak to him again. But most of all I was incredibly pissed because I knew that was a luxury I didn't have. I would *never* desert him.

### **Stalemate**

Later that evening after relaxing on my sofa and watching the news for awhile, my anger subsided some and I called him, hoping that he, too, was in a better mood.

No answer.

I knew he was there because he didn't drive anymore. Awhile before he had started not answering the phone when we'd had a bad fight. I went to bed, frazzled from the day's events, and fell asleep stroking Peter, my beloved little Shih Tzu, who curled up with me and intermittently licked my face.

I spent the next morning working on my grant but had trouble concentrating. My mind kept going back to the terrible scenes Ed had made the day before. But mostly I was sad that our relationship was in such a bad state. I didn't bother calling in the morning because I knew he wouldn't answer. In the afternoon I couldn't stand it any longer and I tried.

Still no answer.

When he didn't answer later that evening I realized I was going to have to end this stalemate in the only manner that would. I would have to write a formal letter of apology. As infuriating as it was, I'd have to apologize even though I'd done nothing wrong. Recent experience told me it was the only way to move on. I needed him. He needed me. So I wrote the damn letter.

Dear Kitty,

I'm sorry I upset you yesterday. I didn't mean to. I was just stressed out from my job. Please forgive me.

Love,

Kitty

PS: Peter is crying because he misses you.

He loved Peter and I hoped saying that Peter was crying might soften his heart. We often talked about Peter as though he were a person. I knew that, just as he'd done the other times I'd written such letters, he'd pick up the phone and call me and we'd have a pleasant talk. Neither the fight nor the letter would ever be mentioned. Earlier in our relationship this used to happen once or twice a year. Now it was happening once or twice a month.

I was near tears as I went out into the cold and dropped the letter in the ice-covered mailbox on the corner, wondering how many more times I was going to have to go through this abusive routine.

## **Chapter 3: A Changing Relationship (2004)**

### **The Juggling Act**

Another year had passed since that day I'd dubbed 'The Day from Hell.' Ed's mental functioning had continued to decline slowly and he was becoming even more difficult to get along with. I was at the end of my rope. I really was.

Desperate, in a last-ditch effort to save my sanity and the relationship, I'd invited my friend and colleague, Irene Moore, to lunch to discuss 'a problem with Ed.' Irene was a geriatric social worker, and so was uniquely qualified to give me both professional and personal advice. She'd also met Ed once, ten years earlier, when I was 44 and he was 81. Like all my girlfriends, she'd found him enchanting.

On my drive to the Medical Center, where we were to meet in the hospital cafeteria, I kept obsessing about the training grant that was due the following Monday. It had become a challenge to take care of Ed and do my job at the same time. These grants were tremendously demanding. Congress had set aside several pots of money for the Health Resources and Services Administration to competitively distribute to university family medicine departments. I'd been preparing those grants since I was promoted to be the grant writer in the Family Medicine Department at UC back in the early '80s. I'd become quite the expert and had an unusually high success rate, having brought in around \$15 million over the years. One of our faculty members referred to me as the department's 'secret weapon.'

I truly enjoyed my job, yet the problem was that there were three to four of those grants per year and they were all due around the same time. They were extremely time-consuming to write. They ran around 75 pages and the instructions alone were over 100 pages. I ended up working 12-hour days, including weekends. The work was physically and mentally exhausting.

### The Cardiology Professor

To make things worse, I often did freelance medical writing and editing. I enjoyed having the extra money even though it took up more of my precious time. My most interesting – and challenging – client was a distinguished silver-haired cardiology professor at the UC Medical Center. He was a brilliant and pioneering thinker; a competent and compassionate physician. His only failing was that he couldn't *peak* coherently. I'd met with him the previous Tuesday to find out what he wanted me to write for him that day.

He'd started off by telling me, "I need something for the – uh, you know, these damned insurance companies are so – well, they don't understand that patients who have heart attacks are – the companies are so greedy they – this patient of mine needs a lot of rehabilitation – his wife called the ambulance and they arrived within five minutes – and, uh, they thought it was a heart attack – I ordered a physical therapist for him last week – his insurance company – uh . . ."

It was perfectly obvious why he needed a professional writer to help him.

"They said – and he really needed the therapy and – uh, he needed a nurse, too, and his company, Blue Cross – I ordered both the physical therapy and the nurse and he needed – even though his son and daughter-in-law - he needed it at home – and so I told him and his wife – uh, she's an executive at P & G, I told them I would –"

"Do you want me to write a letter to the insurance company?" I interrupted, dizzy from listening to this meandering monologue and making my best-educated guess as to what he wanted me to write.

"Yes, – the patient," he continued, "who lives in Indian Hill, and uh, his insurance company – he's a millionaire, you know – uh, needs the therapist and nurse and a dietician would be helpful – he's still in the hospital and his wife said that Blue Cross – uh – to go to his home and these damned insurance companies – he had a heart attack last week – it was a bad heart attack and he's taking several medications."

He had finally finished his sentence.

And so it went. It took ten minutes just to clarify that yes, he did want me to write a letter to the man's insurance company to persuade them to pay for the physical therapist, nurse and dietician to provide their services in the man's home. Then we moved to a discussion of what *details* should be in the letter. Finally, after another ten minutes I had



clarified all the pertinent facts. I wrote the letter. The insurance company paid for the services.

I loved that man dearly. He was incredibly sweet and praised me for every thing I wrote for him, whether it was a letter to an insurance company or an NIH research grant. But working for him drove me nuts. I eventually quit and turned him over to my best friend, Marsha, who had the patience and good humor to work for him until she moved to San Francisco a year later. I don't know what he did after that.

### **Log Cabins**

While I'd enjoyed having the extra freelance income, that work, my real job and my responsibilities towards Ed had turned into a juggling act that stretched me to the limit. So naturally I was really looking forward to my upcoming vacation to the Pines of Lake Patoka Village in southern Indiana, a four-hour drive from Cincinnati. Ed always referred to it as 'Lake Poka.' I was going for ten days as soon as my grant was finished.

I'd been taking vacations – personal retreats, really – to log cabins in the woods since the '80s, and they were central to my emotional well-being. I'd try to go at least twice a year for a week or two. Those retreats allowed me to get away from everyone and everything. There were no phones in the cabins and no cell phone or Internet service in the area. I had twenty-four hours a day every day to do anything I wanted, whenever and however I wanted. I had total freedom in nearly total isolation. It was heavenly.

The first thing I'd always do upon arriving at my cabin was close the blinds. I'd only go out to take Peter for a walk or drive the eleven miles to the nearest grocery store. If I'd happen to run into another vacationer while outside with Peter I'd say hello but never stop to talk. I didn't want to see or talk to anyone.

Peter was an excellent companion on these trips. Beige and white with huge brown eyes, his tail never stopped wagging. I was so happy I'd chosen him. Actually, I didn't choose Peter. He chose me. Like the Mona Lisa, his eyes followed me everywhere I went in the pet store. I left that store and went to another, but there were no puppies as beseeching as Peter, so I returned to the first place. Peter's eyes locked onto me again the instant I entered. So that settled that.

Peter was the cutest little Shih Tzu puppy you ever saw. And that's not just my opinion. I was walking him one day when a lady stopped her car and stuck her head out the window. She said – and I quote – “That's the cutest puppy I ever saw!” So that made at least two of us. Another time I was sitting in my car outside the Oakley United Dairy Farmers – or the UDF as we called it - on a hot summer day eating a strawberry ice-cream cone. As always, I took a few licks, then held it over for Peter to lick a few times. Well, just when Peter was taking his licks I heard hysterical laughter. I looked over and saw a lady in a car parked next to mine. She was watching us and apparently found our ice cream sharing hilarious.

Once settled into the cabin I'd set up an office on the dining room table with my laptop, portable printer, and office supplies. Some days I'd spend up to ten hours writing – whatever project I was working on at the time. I often worked nonstop, getting up only to eat, go to the bathroom, or take Peter out. It was during these retreats that I wrote, among other things, an autobiography. At the time it didn't seem to be of interest to anyone but me, but I enjoyed writing it nonetheless.

I'd stay up late, sleep in and take naps whenever I felt like it – all things that were most unusual for me. I'd watch the news and reruns of my favorite old TV shows, *Murder She Wrote* and *Matlock*, which Ed always called ‘Meatloaf.’ I enjoyed those shows immensely even though I'd seen most of the episodes. I'd also spend hours at a time playing word games on my iPAQ. Another ritual was making bacon and eggs. That was the only time I ever cooked, and I'd look forward to it with delight. The fried bacon always smelled delicious and its aroma would linger in the cabin all day. It was especially strong when I came back in from the grocery store. Whenever I smelled fried bacon anywhere else it reminded me vividly of those trips. I loved every minute of them and each morning, with dismay, I'd count the dwindling number of days remaining until I had to leave.

### **Difficult Advice**

“Hello, Dr. Marley. Have you been waiting long?”

Irene, short and trim, her long brown hair pulled away from her sweet youthful face, appeared as if out of nowhere.

“Nope,” I lied.

I had arrived a good fifteen minutes early, as usual.

“Just got here.”

Irene, a native North Carolinian, had a lovely southern accent and was always mildly deferential, calling me Dr. Marley, although we were friends. She did it to be charming, and it was. Irene knew a lot about dementia. Not only was she a specialist in geriatric social work, her mother had died from Alzheimer's several years earlier, giving her a tragic personal experience no one should have to go through.

It was noon and the cafeteria was alive with the raucous noise of various dining groups. There were medical students, residents and professors, some in white coats or scrubs. Another group consisted of university staff in street clothes. The third class of diners included those who were there to visit their hospitalized loved ones. You could instantly tell who they were. There was something that made them stand out – their dress, their worried facial expressions or perhaps it was just their general demeanor.

Irene and I went off separately to inspect the multiple serving stations. The fried chicken smelled and looked so appetizing it reminded me of my childhood. My mother used to make fried chicken with mashed potatoes and gravy every Sunday. I decided that was what I was going to have. We met again at the cash register and after paying we picked a booth. Thin ‘Miss Irene,’ as I called her, had selected a nutritious-looking salad, while I fortified my fried chicken with mashed potatoes, gravy, green beans and chocolate cake. *No wonder I'm 65 pounds overweight.*

A few minutes into lunch Irene addressed the issue at hand: “So, how is Ed?”

“Actually,” I began as if flood gates had opened, “he's become impossible to be around. He's incredibly irritable, angry, mean and emotionally abusive.”

I gave her the full details of a recent bad day, when he'd made ugly scenes at both the cardiologist and the grocery store.

“He's like that all the time now,” I said. “Plus, although he always liked his beer, wine and hard liquor, now he's drinking prodigious quantities of it. Even more worrisome, he's drinking before noon, and he drinks into the wee hours of the morning while waiting for his *New York Times*, which arrives around midnight.”

“That doesn't sound good,” Irene said.

“He drinks so much he keeps falling. I’ve had to take him to the emergency room more than once. One day I arrived and found his recliner overturned. When I asked him what happened, first he said he didn’t remember. Then he claimed it had been that way when he got up that morning. I suspect his drinking is not only causing these falls, it’s also contributing to his depression and belligerence. But I can’t convince him to drink less. I love Ed, but I just don’t think I can tolerate this anymore. Yet I can’t possibly end our relationship, either. He couldn’t get by without me.”

My chicken sat uneaten, growing cold, while I dug in my purse for a Nicorette.

“And he’s getting really confused lately, Irene. Last Saturday evening he actually called the *New York Times* and yelled at them because he hadn’t his ‘Sunday paper r-r-received yet.’” When I reminded him it was Saturday he got angry. He gets angry over the smallest things. We used to be able to discuss things we disagreed about, but if I express a contrary opinion now, he becomes hostile. It’s maddening.”

“Hmm . . . Well, Dr. Marley,” Irene said, looking at me with empathy. “You do have a problem indeed. I think he may be dementing.”

“Dementing?” I repeated, immediately dismissing the notion. “Well, I don’t care what he’s doing. I just don’t know how much longer I can take it,” I leaned forward, put my elbows on the table, and rested my head in my hands.

I didn’t want to hear about or think about dementia.

“You have the option of ending the relationship. You know that, don’t you?”

That made me snap to attention.

“Irene, I can’t do that,” I said, as though it was the stupidest thing I’d ever heard. “I love him. Besides, I told you, he couldn’t *survive* without me. How could I just abandon him?”

“I know women who were married for as long as fifty years who, in similar situations, divorced their husbands.”

In retrospect I know she was gently trying to tell me that Ed couldn’t help it, that his behavior would likely not change because he had dementia. At the same time, she was trying to tell me that, while I couldn’t change Ed, I did have options. I didn’t have to take the abuse; I could leave.

“How could I possibly do that? It would be morally reprehensible. He couldn’t make it through a single week alone. I *have* to take care of him. If I don’t, no one will,” I said. “I have no choice.”

For an instant I fantasized about how wonderful it would be not to have to endure his abusive outbursts, but then I imagined Ed sitting in his recliner, unaware of my quandary and the repercussions it could have for him, I was pretty sure he was watching Reagan’s funeral, as if it were the only thing in the world that mattered. Reagan was one of Ed’s heroes, and the fact that he’d died of Alzheimer’s was affecting him profoundly.

I dismissed the thought of leaving him. I would *never* leave him. *Never*.

“Well,” Irene said, “in that case, perhaps we need to talk about how to manage the situation.”

“Yes, please,” I said, hunting for yet another Nicorette.

“There are three things I can advise you,” she said, pushing her still half-full salad plate aside and laying her fork across it. She took a drink of her iced tea then fixed her eyes on mine, as though ready to reveal some highly-classified secrets. “First, don’t bring up topics you think may upset him. Second, if he starts to get agitated, change the subject. And third, agree with everything he says, no matter how absurd.”

I was speechless. That would change our relationship completely.

“If I follow your advice we can’t discuss politics,” I said. “Our views differ so much that would violate rule number one. And I couldn’t talk about my job or personal problems because he’d get upset if I didn’t take his advice. That would violate rule number two. And quite seriously, I can’t imagine myself agreeing with everything he says because he’s so often wrong. I can’t imagine bowing my head and going along with whatever nonsense comes out of his mouth.”

“I can’t promise following these rules will stop all the fights,” she said. “But it’ll help. Why don’t you try it for awhile and see what happens?”

“But Irene,” I said. “I can’t agree with him when he says stupid things.”

“When that happens, just ask yourself, ‘Do I want to be right or do I want to have peace?’”

That was a difficult question. If I followed her advice it meant my relationship with Ed would change dramatically. We’d no longer be able to talk about whatever we wanted, or whatever topics naturally arose. And – what I dreaded the most – I wouldn’t be able to be honest. No

matter how much I disagreed with him I'd have to pretend to concur. Our relationship would become superficial, dishonest and unreal.

"There is one more thing I'd like to suggest to you," Irene said.

"What is it?"

"Well, considering the stress you're under, maybe you should get a therapist. A professional counselor you could talk to about all this."

"Hmm," I said, cocking my head to the side and thinking about her proposal. "You know, Irene, that just might be a very good idea. Can you recommend someone?"

"Yes. My friend Becky sees a therapist and just loves her. In fact, I *think* I may have her number in my phone. Let me look."

She did have it, and wrote it down for me on the back of an old grocery list. I folded it carefully and placed it in my wallet as we got up to leave. Outside we hugged affectionately and parted.

And that's how it came to be that as Ed became more demented I agreed with him about more and more. Important things, unimportant things; political issues and mundane day-to-day issues; silly things and serious things. As many demented people do, he soon began mixing up day and night. One afternoon, when he woke up disoriented after a nap, I agreed with him that it was the middle of the night. And late one evening a few weeks later, I agreed with him that it was noon. Although the whole plan seemed ridiculous at first, I found that it did stop most of our nasty fights. I eventually realized it really was better to have peace than to be right. But it felt like our relationship was changing right before my eyes, dying piece by piece, and I wondered where it would end.

### **Becoming Soul Mates**

The truth is our relationship had disintegrated once many years before. Ed and I had lived together pretty much in bliss for three years. It was 1978; I was 28 and he was 65. Over the course of only three months our previously benign arguments became more frequent and turned into ugly fights. And we didn't make up within ten or twenty minutes like we did before either. Sometimes we didn't speak until the next day. Sometimes one of us would go into the bedroom, slam the door and stay there reading all day. Or maybe we'd both sit stiffly in the living room watching TV silently. At bedtime it was understood that the one who went to bed first got the bed. The other got the sofa, which was beautiful to look at but agonizing to sleep on. I always tried to be the first to go to bed.

We both stopped smoking at the time, which probably didn't help much. Ed quit cold turkey and never smoked another cigarette in his life. At the time he proudly announced, "*Nemo liber est qui corpori servit*," which he said meant, "No one is free who is a slave to his body." Unfortunately, I remained a slave to my body. I quit smoking with the help of Nicorette but ended up being addicted to Nicorette instead of cigarettes. Great.

To make things worse, Ed's eccentricities became more pronounced. He behaved as if I were his maid. He gave me lists of things to clean and insisted that I learn to cook – for him. He began to dislike my two closest friends, Marsha and Allen.

Marsha was my oldest and dearest friend from college. We'd met in grad school when we were both just starting our master's degrees. Hers was in oboe performance; mine in music history. Both Ed and Marsha's boyfriend, Jim, were homebodies, so she and I were constant companions, whether studying, running errands, shooting the breeze, going for long bike rides or attending the opera. Marsha and Ed were close, too, and the three of us often enjoyed lovely dinners together when Jim was out on a gig. Ed referred to the time I spent with Marsha as "Martializing," which was cute at first but then he became jealous of the time I spent with her and accused us of having a lesbian relationship. I'd never seen this hurtful and mean side of Ed.

Ed's reaction to my friendship with Allen was even worse. A music theory graduate student, Allen was a tall, blond, blue-eyed Adonis with a brilliant mind and an ever-present sweet smile. We were quite close and passed many pleasant hours together. Usually we met over rank coffee at the college's 'scrounge lounge' or for slightly more appetizing lunches at Frisches, a nearby restaurant. Ed, who never met Allen but heard a lot about him from me, was convinced I was having a 'r-r-romantic r-r-relationship' with him. To this day I can't comprehend why I ever told Ed about my friendship with another man. I should have known that he'd be jealous. Every time I came home a little bit later than expected, Ed would ask accusingly, "You've been with *Allen*, haven't you?"

While often that was true, our relationship was purely platonic. Allen was gay. I had told Ed repeatedly, but he wouldn't believe me. Once he even called a mutual friend to inquire about my relationship with Allen. So there I was being accused of having a heterosexual relationship with a gay man and a lesbian relationship with a heterosexual woman. The irony of it all.

As the months passed, our fights became evermore intense and stressful. And when Ed stopped going to bed at the same time I did and stayed up later than usual to read, our intimate relationship ended. Finally, I couldn't take it anymore. Despite my enduring love for Ed, I decided to end the relationship. So early on a blustery November day, with dark storm clouds looming overhead and leaves turbulently rustling all around, I stormed out, taking my meager belongings and the *Very Little Kitty* with me.

I missed him terribly immediately. I ached to be held by him, caressed by him; I ached to hear his charming accent, his bold theories about all possible things under the sun. I wanted to stretch out on his sofa as before, resting my head in his lap, talking for hours about whatever topics might arise. I wanted to have 'dee-ner' with him. Go to the movies. I wanted to cuddle and sleep as one in his little twin bed.

I was living in a fog, not caring about my job or anything else. I didn't want to see my friends, not even Allen or Marsha. I felt numbness and despair as the days passed. Yet every time I thought about going back to him I remembered the horrendous fights and vowed to remain alone. With only the *Very Little Kitty* to keep me company in my tiny apartment, nothing could have prepared me for what happened next.

It was the most amazing thing. Ed suddenly appeared at my apartment building one evening two weeks after I'd left him. It was a bitterly cold day, the temperature a freezing ten degrees. My teeth were chattering as I rushed to my car to go buy some food for Kitty at Kroger's. The frigid air hit me full force and took my breath away. I silently cursed at myself for not having had the common sense to put on my gloves. Just as I opened my car door, the freezing metal stinging my bare hand, I saw him coming around the corner.

"I am thinking about moving and was wondering 'eef' any vacant apartments are here in your building."

I couldn't believe my ears. His apartment had a glorious view of the Ohio River. I was living on a noisy street in a run-down efficiency apartment building occupied exclusively by students. The view was a parking lot overgrown with weeds. Why on earth he'd want to move to my building was beyond me.

"No, there aren't any apartments available here right now," I said truthfully, shuddering in the cold.

"Really? That's too bad. Well, would you like to have 'dee-ner' this evening with me at the Edgecliff?" he asked, shivering as he spoke.



I hesitated, not knowing whether he wanted to rekindle our romantic relationship or if he was just lonely and wanted a dinner companion. I did *not* want to return to him and our vicious arguments, but I still loved him and thought it would be wonderful to be close friends. Yet I thought such an arrangement unlikely because in my experience, men *never* wanted to be 'just friends' after a romantic relationship ended.

What I didn't know back then was that Ed was in the habit of staying close to all of his former lovers and his former wife, Charlotte. Ed cared about women for romantic reasons, but he also loved them as people. When the romance was spent, the love was still there. Former lovers of his were spread across the U. S., France and Romania, and probably in countries I didn't even know he'd visited. Ed once had a relationship with a wealthy Cincinnati woman. When their romance ended, not only did they remain friends, but Ed began courting her daughter. Only Ed would have the audacity to do that! When *that* romance ended, he stayed close to them both, and even befriended the daughter's new husband.

At Ed's memorial service many years later I was tempted to ask this mother and daughter, and any other 'special friends' present to stand and be recognized. I imagined that first one little lady in the back would tentatively rise and look around, a little embarrassed. Then another would rise. Then another and another, until many would be standing, likely most of the women in the room. Of course I didn't do it. It was just a mischievous idea.

Despite my reservations, however, the temptation to spend time with Ed was irresistible. "Okay," I answered to his dinner invitation, thrusting my frozen hands into my coat pockets, "but let's go to Lenhardt's." I vowed not to go home with him after dinner, no matter what.

Ed was as charismatic and 'gentlemanly' at Lenhardt's that evening as he'd been at our first dinner together at the Edgecliff. We braved the dreadful cold, rushing into the restaurant to escape the stinging wind, hung up our snow-covered coats in the entry room bar and waited to be seated. Ed politely requested a table in the more intimate dining room off to the right, as usual. We had a wonderful dinner of Wiener schnitzel and sat there quietly, the restaurant's bold coffee keeping us alert for more than an hour after we finished eating. The time flew by quickly as we caught up on everything that had happened in the two weeks since we'd split. We called

each other “Kitty” without giving it a second thought, as though we hadn’t ended our relationship at all.

As I’d anticipated, when we were ready to leave, he wistfully asked, “Would you like to come home with me?”

He put his hand on mine and looked at me affectionately, a gaze that made me feel sad. His hand was smooth and soft, bringing back a flood of bittersweet memories from our earliest days together. He sounded as sad as I felt. I wanted to go back to the romantic relationship we’d had. I was ever so tempted to move back in with him that very night. But I stayed true to myself.

“I don’t think so,” I answered, folding my napkin. “I just want to be friends, Kitty. So,” I said with all the self-discipline I could muster, “could you please take me to my apartment?”

He did, and as his old blue Pontiac’s tail lights disappeared down Stratford and around the corner onto Probasco, a deep sense of loss filled my heart. I knew our old relationship would never work again. I walked inside, closed the door and spent the night with the *Very Little Kitty*.

Ed kept calling and inviting me to ‘dee-ner’ and I kept accepting. We slowly began resuming other activities as well. We’d go to foreign films and classical ‘moo-sic’ concerts. After every ‘date’ he’d drop me off at my apartment. Weeks and months went by, and the pain of separation after an evening together decreased, then stopped.

At first Ed tried to resume our sexual relationship, but I resisted. I really wanted to be friends – no more, no less – and I made that clear again and again. After awhile he accepted that, and the most beautiful life-changing process began to unfold. We became nearly inseparable. When he wasn’t teaching and I wasn’t at school, we were together, if not physically, then on the phone. Whenever I’d stay late at the Edgecliff, rather than drive home in the wee hours of the night, I just slept there, all cozy and curled up in bed with Ed. It was as though our bodies were melded into one in a warm, though not sexual, expression of love. In that state, sleep was delicious and came easily. Waking up – gradually gaining consciousness and realizing we were nestled together – was a tender moment each and every time. I felt safe, cared for and loved.

Little by little we began traveling together again. We visited his ‘colorful’ Romanian friends in Pennsylvania, who put us in the same bedroom. I never knew whether they just assumed we slept together or whether they had pulled Ed aside and asked him. We also went to see my equally

colorful ‘moo-si-cian’ friends in California. They, too, assigned us to the same room and it was fine with us.

Then we had several relaxing vacations at Kentucky State Parks. On our trip to Lake Cumberland, we stayed in a ‘Wildwood Cottage.’ A pair of masked raccoons visited our porch every night, waking us up with their commotion. We’d tiptoe to the living room window, trying to catch a glimpse of them before they scampered off, probably to someone else’s porch. We even went to ‘Ee-taly’ – the trip he’d so precipitously invited me on during our first ‘date.’

And so it was that our love began to grow over the years until we became stalwart life-long partners. It was a relationship that ever deepened and transformed itself as our needs from one another evolved. It wasn’t always easy, though. Our relationship would be tested by daunting challenges over time.

### **Like the Treasure You Are**

In our early days together Ed had opened a whole new world to me. He taught me better taste in clothing, took me to classy restaurants, and introduced me to fine wines and foreign films. We vacationed in exquisite places I never could have afforded on my own. Yet far more important is that he gave me what I needed the most. He was gentle and affectionate, holding my hands while looking into my eyes, listening intently, showing me he cared about what I said. He admired me. He encouraged my every endeavor, praised every accomplishment. Although he was the one who was supremely intelligent, he made me feel as though I were brilliant. He made me feel special. He supported me in everything I did, treated me like a treasure, and loved me unconditionally.

Right from the start Ed was there to comfort me. I was immeasurably sad about leaving Guido to be with Ed. I *wanted* to be with Ed and stood by my decision, but I still felt love for Guido and missed him. In the beginning I often awakened in the night and, overcome with sadness, slipped out of Ed’s little twin bed and tiptoed into the living room. There I sat on the sofa and quietly cried over Guido. Ed, who’d wake up every time, came out and sat beside me. He held me in his arms, telling me how well he understood me and how sorry he was to see me suffering. This – more than anything else he could have said or done – revealed the depth of his love and the strength of his character. After all, I *was* crying over another man.

Ed was the consummate comforter. At the same time he was comforting me, he was also consoling Amy, the young woman he'd left to be with me. I vividly remember him talking to her on the phone nearly every evening for several weeks after their breakup, talking with her with genuine compassion. I tried not to be jealous of the time he spent on the phone with her. After all, I was the one he'd chosen.

And it wasn't just Amy and me. I witnessed Ed comforting countless people throughout the years I knew him. I would often arrive and find him on the phone, and just from hearing his side of the conversation I could tell to whom he was talking and for what reason. He made time for those people – however much time they needed – and genuinely cared about them.

I especially remember his frequent lengthy calls with the Romanian housekeeper – I never knew her actual name – who had divorced her mentally ill husband and was struggling to single-handedly raise two teenaged girls. One of them was constantly in trouble with the law; the other had severe mental health problems. Though he was far from being an expert on parenting, Ed gave her a lot of advice, but mainly he was just available when she called, always listened and always showed deep empathy. I could tell her struggles affected him profoundly.

One night I listened to his end of another phone conversation that would become eerily relevant to us.

“Yes, I understand you so well.”

“Oh, my. That's so sad.”

“Really? I can only imagine how difficult that must be for you, but you need to be strong and continue on with your life. You are still a healthy vibrant woman and need to try to stay active. You should go out with your friends more.”

“Yes.”

“Yes, I know that's hard, but you have to fight your sadness. You can also spend more time with your children and grandchildren.”

“Is that so? It's heartbreaking. I'm so sorry.”

“You mean he doesn't recognize you at all anymore? That must be so painful.”

He was talking to Anna Huvos, the wife of Kornel Huvos, a former colleague who had developed Alzheimer's. For months Ed had long talks with her as her husband's mind deteriorated. He was so distressed after these calls I had to try to cheer him up but was never successful. He

took on her suffering as his own, and thus, I suspect, relieved hers for a few moments. Little did I know that some day I'd be having the same exact talk about Ed with one of *my* friends.

I learned to be patient. If he was on the phone, I knew to just sit down and wait until he was finished. He wouldn't tell his conversation partners at the other end that he had a guest and would have to call them back later. He just kept talking until the conversation came to a natural conclusion, no matter how long it took. Often I was displeased that he kept me waiting for so long. It was only later that I began to admire his steadfast empathy for others.

His compassion for me was just as bottomless. I remember one early June evening back in 1978 when I'd just received my PhD and couldn't find a job in my field. I stood on Ed's balcony smoking a cigarette, staring blankly at the coal-filled barges inching ever so slowly up the river as I composed a suicide note in my head. Not that I really intended to kill myself. I was just daydreaming about it. By then I should have gotten a position as a university professor of musicology, but hadn't yet found one. That was depressing even though I knew the job market was flooded with PhDs in musicology and most of my colleagues hadn't found jobs either.

Even more depressing was that since I had to support myself somehow, I'd signed up with the University of Cincinnati's temporary secretarial pool. The situation became worse still when my first secretarial assignment was at CCM, from which I'd just received my doctorate. Not that I had anything against secretaries, but I didn't need to spend ten years in college, write a dissertation, and earn a PhD to become one. I felt humiliated being a secretary, working in plain view of the current year's innocently-optimistic graduate students and all my former professors.

A few months later I was assigned to the Department of Family Medicine as the secretary of the Associate Director, Dr. Frank Colon, who, when he introduced me to people, always added that I had a PhD. He was proud to have a secretary with a PhD, but his introductions made me feel degraded. I didn't know it at the time, but that initial menial job would pave the way to a stellar career.

Dr. Colon was in charge of writing grants; he wrote them out longhand and I typed them. That's how I learned to write grants, and pretty soon I started making suggestions for improvements here and

there. He liked them, and a few years later, when he decided he didn't want to be responsible for grants anymore, I was put in charge. I did have one offer for a teaching position at that time, for a part-time job at the University of Michigan at Ann Arbor. But I didn't take it. It didn't pay enough to support me and I didn't want to leave Ed for something that minor.

I eventually stopped looking for a teaching job altogether. I was crushed. My mood was volatile, although deep down I was in a more or less constant state of depression. Sometimes I exhibited what Ed referred to as 'cosmic silences.' I'd sit on the sofa and silently stare into space for hours at a time. There were times I wanted to kill myself. I never tried to do it, but I fantasized about it. A lot.

Every time I thought about killing myself, I concluded that I shouldn't throw away the chance, however slim, that my life would get better. I had endured a pretty bad childhood with unfit parents, and couldn't bear the thought that I might have gone through all of that only to miss what might be a later *good* part of life. And I was right to have that hope. My later grant-writing career turned out to be more rewarding personally and professionally than I ever could have imagined. And my life with Ed provided an infinite amount of '*good*' in my life.

When I think about it now, memories of that time haunt me. I think rather than wanting to kill myself I just wanted to escape the pain. I would have liked to go to sleep and not wake up until the depression was gone, no matter how many days, weeks, or months it would take.

Instead, I suffered from insomnia and began drinking. At first just a beer or two at bedtime to make me sleepy. Then three, then four. After that I switched to wine. At one point I was drinking almost an entire bottle of wine every evening. After about a year I decided to stop drinking completely and I did. From one day to the next. It was simply expensive and added to my weight problem. I didn't know what a hangover was until I stopped drinking. All of a sudden I felt so much better in the mornings.

I know now that this period must have been difficult for Ed. When I was most depressed he essentially lost me as a companion. I didn't want to talk. I didn't joke around or play games. I didn't want to go out to dinner or the movies. I didn't want to be close emotionally or sexually. I didn't want to do anything. But he never complained. On the contrary, he was patient and understanding, unconditionally compassionate and

loving. Many evenings we sat together on the sofa while he held me in his arms and comforted me. He listened when I expressed my sorrow and despair; and he was there for me when I was completely silent. Sometimes we sat at his kitchen table and he'd make Turkish coffee, thick as mud with a smidgeon of foam on top. We'd sip our coffee and smoke, and he'd look into my eyes.

"Kitty," he'd say. "It will be okay. Believe me. You *will* get a university teaching position." And he would add even more assuredly: "I am certain one hundred percent. Just keep applying, and you will be hired one day. And it will be *soon*. Don't despair." He'd rest his hand on mine and continue: "I can assure you it will work out."

His voice exuded confidence; his caring was always clear. He repeated this speech in hundreds of variations time and again. This was Ed at his best.

He could have ended our relationship, and no one would have blamed him, least of all me, considering how unpleasant and stressful those depressions must have been for him. But as far as I know, he never even considered that option. He was my rock. He was there for me no matter how far away I was from him. He wasn't able to make the deep depressions go away, but his steadfast love, caring and support made them far easier to bear. I have often shuddered to think how I would have managed those dark days without him.

During Ed's last years, people were often telling me – admiration and wonder reverberating through their speech – how lucky he was to have me because I devoted my life to caring for him, enduring so much physical stress and emotional turmoil. I always resented that. Did they really think I would *desert* this man who had done so much for me and meant so much to me? But then again, they didn't know any better. They didn't know us 'back then.' They didn't know everything Ed had done for me. They didn't know that no matter how much I did for him, how much I sacrificed for him, *I* was the one who had been lucky.

One evening back in 1975, when Ed and I had just gotten together, he was sitting at the end of the sofa, as usual, and I was stretched out with my head resting in his lap. We'd been talking about music – the features of Classical music versus Baroque, my preference for vocal music and his for orchestral, my love of Italian opera and his disdain for all opera, the stylistic differences between J. S. Bach and his sons, and so many other intricate musical details we loved to discuss.

“How did you get interested in learning to play the clarinet?” he asked, lighting a cigarette.

“My uncle Francis played the clarinet. He died at age 20 – he was hit by a car – and when I was trying to decide what instrument to play my dad suggested the clarinet. As a tribute to his brother, I guess.”

“Did your father play an instrument?” he asked, moving his hand from my shoulder and resting it on my arm.

“Yes. In fact, he came from a musical family. His father and three brothers all played instruments. One of them even became a professional musician.”

“What was your father like?” he asked. “I’d really like to know about him.”

“Oh, he was a *monster*. I’ll tell you some other time,” I said, reaching for my pack of Salems.

“You keep saying that. I wish you would tell me. It’s hard to believe anyone could be a monster to you, Kitty.”

My body stiffened. I stared into space as I was silently trying to construct a single sentence that would convey once and for all what my father had done. It would have several parts and I wanted to get them in the right order. Most of all I wanted this one sentence to tell Ed everything that mattered. That my father had raped my soul.

“What are you thinking about?” he asked.

I didn’t answer right away. Part of me didn’t want to answer at all, but another part wanted Ed to know everything there was to know about me. I turned my face away and began.

“From when I was seven until I was about fourteen, instead of spanking me, my father punished every little thing I did by making me strip and then savagely and sadistically whipping me with a belt.”

As soon as I said it I felt naked. Violated. Raped. I was afraid to look at Ed. I wondered what he was thinking. That I’d been a terrible child who deserved such punishment?

There was a moment of silence then I looked at him. His eyes were glistening.

“I’m so sorry,” he said. “No one should ever treat you like anything but a treasure.” Tears formed in his eyes and slowly dropped on his cheeks. I watched as they cascaded down his face and fell onto his shirt.

“I’m sorry,” he said again, crying openly.

Yes, *I* was the one who had been lucky.



## Chapter 4: Facing the Truth (2005)

### Time to Move

I was sitting on Ed's sofa eating a fried bologna sandwich when he showed me the letter. I knew it was going to cause a disaster, but not even I could have predicted the enormity of the catastrophe that followed. The letter said quite simply that the Edgecliff had just been sold and was going condo. Ed had lived at the Edgecliff for more than thirty years. He was 92 years old. His memory was fading and confusion was a constant companion.

The elderly often become disoriented when they move to a new home, and Ed was already disoriented enough. He'd been having trouble with even the simplest things. Bathing, dressing, and managing his dentures had become a challenge, let alone more complex tasks such as handling his finances or keeping track of his numerous doctor appointments. In my continued denial, I still considered all those to be isolated issues, and not part and parcel of a more menacing problem.

The letter was ominous and Ed was distressed. His hands shaking more than usual, he sat across from me in his recliner, a bottle of Heineken and a slice of cherry pie on the little side table. He took the letter from me and read it aloud, emphasizing the part that said current residents had only three months to either buy their apartments or vacate the premises.

"They can't do this. I've 'leeved' thirty years here. I'll r-r-refuse to move. I'll talk to Fabe. I know him personally. He'll let me stay," he said, taking a sip of his beer. His speech was gruff, but I could tell he was very upset by the whole situation.

"No, Kitty," I said, peeling off the backing of a Nicorette. "I'm really sorry, but they *can* do it. Mr. Fabe sold the building. He can't make any decisions about it any more."

“Yes, he can. With his money and prestige he can convince the new owner to let me stay.”

Now Ed was the one in denial. Or so I thought. The truth was he was too demented to understand the situation.

I was as distressed, if not more so, than he. I didn’t want him uprooted from his home and everything that was familiar to him. I was not privy to his financial situation – that was one of his deep secrets – but given his perpetual thriftiness with himself (though not with others), I assumed he couldn’t afford to buy the apartment.

There were other elderly tenants at the Edgecliff. None were going to live much longer. It would have been far more humane if the new owner had just let them stay as tenants. Ed’s case was the most heartbreaking. He was the oldest and frailest of them all.

Ed decided to make an appointment with the new owner, hoping to convince him to let him continue to rent his apartment. We got all dressed up and went to the meeting together. When we arrived, I looked out the office window and saw that the new owner’s Bentley, which was usually parked conspicuously under the portico, was just arriving.

A man wearing an exquisitely-tailored charcoal grey suit that hinted at his financial status and a woman in a stunning black dress got out of the status symbol. They didn’t look like the kind of people who’d give a damn about the elderly. Precisely one minute later the office door opened and ‘Mr. and Mrs. Bentley’ – I never knew their real names – regal in their bearing, entered. I was worried how Ed would handle himself. In those days you never knew when he’d act ‘normal’ and when he’d act, well, like a demented elderly man.

“Gud oft-air-noon, sir,” Ed started off in his most formal manner, shaking hands with ‘Mr. Bentley’ and introducing himself. “I would like a business ‘ee-shoe’ to ‘dee-scuss’ with you if you be so kind.”

“Certainly,” the man said, “What’s on your mind?”

“I have been ‘leev-ing’ here for nearly thirty years at the Edgecliff,” he said, sounding perfectly lucid. “As you know, it’s quite a wonderful place with the r-r-restaurant, the pool, the truly magnificent view of the r-r-river, and all the other amenities, and so I have come to ask ‘eef’ you would be so kind as to allow me to continue ‘leev-ing’ in my apartment and r-r-renting it. I’m sure you understand that at my age I wouldn’t want my apartment to buy.”

No one would have guessed that, earlier in the day, Ed had held the receiver in his lap instead of to his ear while trying to talk on the phone to one of his former colleagues.

"I sure do wish I could let you stay as a tenant. You seem like a nice gentleman. But I'm a businessman and I can't do it. I have to pay my bills every month."

He smiled at Ed then abruptly turned away and began talking to the building's manager. The meeting was over. I was right. He didn't give a damn. So Ed decided to get some professional advice.

### **Legal Advice**

The mild spring breeze brushed my hair against my face and made me wish Ed and I were at the ocean instead of in downtown Cincinnati to see his attorney, Stuart Susskind. Ed had a warm personal relationship with Stuart, who had a rather unique way of eliciting information from people. Sometimes, instead of asking direct questions people might not wish to answer, he asked other, seemingly unrelated questions that would lead to the information he wanted. I met him in 1995, when I was 45. Ed, who was 82 at the time, had taken me there to have my will prepared.

Stuart was curious about my relationship with Ed, but instead of asking me about it directly, he asked what I called him. Clearly he wanted to know if I called him 'Dr. Theodoru' or 'Ed.' That would tell him a lot about our relationship. Considering I called Ed "Kitty," I hesitated quite a bit with my answer, finally telling him that we were on a first-name basis. I don't know what Stuart thought about the fact that it took me so long to answer such a simple question.

Ed always had trouble pronouncing Stuart's name properly.

"I need to call Stu-ART today," Ed once told me when he wanted to get Stuart's advice about something.

"No, Kitty," I said. "His name is 'STU-art.' The stress is on the first syllable."

"Yes, that's what I said – 'Stu-ART.'"

I could tell Ed thought he'd imitated my pronunciation perfectly.

"No," I said. "'STU-art'. Not 'Stu-ART.' Say 'STU-art.'"

"Kitty, that's what I just said – 'Stu-ART!'"

I gave up and, in Ed's presence I referred to him as 'Stu-ART.'

Ed's quirky accent and idiosyncratic use of the English language was often amusing. Although his vocabulary was rich and sophisticated – certainly more so than mine – he did make some rather endearing mistakes. He once informed a woman interviewing him for a job that he was 'a bad typewriter.'

"Go get a chopstick from my medicine cabinet," he told me one time when my lips were chapped. And once while in the car I needed a Kleenex and he told me, "Look in the glove department." Ed was a horrible driver and often asked me why other cars were "horning" at him.

Ed was always returning shoes because "they hurt my feet fingers." And one day he excitedly announced: "Kitty, we just got a fitting room!" I couldn't understand why the Edgecliff would want a tailor in the building, but nonetheless, I followed him to see the new room. It was a workout room.

But by far my favorite was when he asked a clerk at Walgreen's, "Do you have any hangovers?" He wanted clip-on sunglasses. You know – they 'hang over' your regular glasses. Needless to say the clerk was taken aback.

Ed had a strong accent. For one thing, he couldn't pronounce 'th.' That made for a rather interesting name change for his friend Henry Sexton III, whom he always innocently called Henry Sexton 'the *turd*.' Try as I might, I could never teach him how to pronounce 'third.' Not only did he have trouble pronouncing 'th,' he didn't comprehend it either. One day he complained to me that a student had greeted him impertinently by saying "Hi, dear." After a moment's thought I started laughing, assuming the student had said, "Hi, *there*."

His accent and unusual formality combined did not go unnoticed by others either. One day he called me at work and asked my colleague, Dr. Gibson, who answered the phone, "Gud oft-air-noon, sir. If you be so kind, may I please speak to Doc-tair Ma-r-r-rie Marley?"

Jay dialed my extension. "It's Bela Lugosi on line 2!"

I cracked up, given that Jay's reference to the Hungarian actor who played Count Dracula in the 1931 horror film *Dracula* seemed so fitting.

Displaying an outsider's insight into the English language, Ed asked me once, "Why do you say in English 'I'm pissed off?' It would be more proper to say 'I feel pissed *on*.'" I laughed and had to agree with him.

We were waiting for Stu-ART in the firm's reception area. Large windows offered a magnificent view of the city below, and the room was so grand I felt out of place in my standard uniform of jeans, tee shirt and sneakers. I was surprised Ed hadn't sent me home to change. Soon Stuart came out and greeted us cordially. In his early sixties, he was of medium height and weight and was wearing an expensive suit, a crisply starched white shirt, a conservative burgundy and gray striped tie, and highly polished wingtips.

He hadn't seen Ed for a few years and I could tell he was shocked. Ed had become so frail and unsteady I had to hold his arm firmly as he walked. It was too bad there wasn't a way to hold onto his mind and steady it.

We followed Stuart into a small cozy conference room furnished with a table surrounded by four chairs, where we all took a seat. Unfortunately, Ed was not as mentally competent as he'd been the day we met with 'Mr. Bentley.'

"Gud oft-air-noon, Meez-stair Sooz-kind," Ed started off, as formal as ever.

"Ed, call me Stuart."

Stuart had told Ed that a hundred times.

"Oh, yes. Stu-ART. Thank you, sir. I have come to obtain your advice about my house where I 'leev.' It's for sale as you may know from all the 'poo-blicity' in the newspaper, and the new owner – an unpleasant man – *anguis in herba* - wants me to buy the building for..."

I didn't know what *anguis in herba* meant but assumed it was something negative about a person. I was amazed Ed still remembered the Latin sayings he'd drop here and there.

"No, Ed. He wants you to buy your *apartment*."

"My what?"

"Your *apartment*," I repeated.

"Yes. My apartment. It would cost \$700,000, which is certainly a lot of money."

"Ed, your current apartment would cost you no more than \$250,000."

"No, Kitty. You're wrong. It's at least \$600,000."

He was getting agitated, but I corrected him again, looking at Stuart.

"It's \$250,000."

"I see," said Stuart. "Ed, what do you want to do? Do you have the money to buy it?"

“Do I have what?” he asked.

“The *money*,” said Stuart, talking more loudly. “Do you have the *money* to buy it?”

“Oh, yes. I certainly have the money,” Ed answered, sounding proud, “but do you advise me to buy it? \$500,000 is quite expensive for a house.”

“An apartment,” I said.

“A what?”

“An *apartment*,” I said, raising my voice, partly so he could hear me and partly because I was getting annoyed.

Noting Ed’s mental condition, Stuart began addressing his remarks to me. Although Ed was confused, he *was* alert enough to realize he was being marginalized.

“Don’t talk to *her*. *She’s* not in charge,” he said to Stuart.

I cringed, but I understood Ed’s frustration and so I nodded to Stuart in agreement. And Stuart tried.

“If you have the money and you’d like to keep living there, Ed, then I’d advise you to buy the apartment,” Stuart said at the end of a rather long and trying conversation.

“Certainly! I will take your advice. With your knowledge and experience you surely know what is best. I will buy my house.”

I let it go.

Stu-ART accompanied us back to the waiting room, shook our hands warmly and bid us farewell. Then Ed and I got on the elevator.

“I’m going to a new apartment to move. And soon!” Ed announced loudly the moment the elevator doors closed.

So much for consulting his trusted attorney. We were back to square one.

I was touched when, years later, as a final tribute Stuart attended Ed’s memorial service. I didn’t expect such a busy attorney to come all the way out to the service. I guess he really did care about Ed. A year after Ed’s death I had occasion to call Stuart and, among other things, asked him about the nature of his relationship with Ed. He told me there were a couple of reasons he felt such affection for Ed. He pointed out that Ed had come here as a political refugee, enduring untold persecution just as his own grandparents had as Jews in their homeland. And, he continued, Ed was such a gentleman and a gentle man that he reminded Stuart of his own father. I’ll always remember that conversation fondly.

There would be another unexpected guest at the memorial service. Just as I was putting the final touches on my eulogy for Ed the phone rang.

"Gud oft-air-noon, ma'am. If you be so kind, might I please speak with Mar-r-rie Marley?"

He had Ed's *exact* accent and manner of speaking, but his voice had a much higher pitch. I was instantly intrigued.

"I'm Marie."

He gave me his name, which ended with the letter 'u,' virtually confirming my suspicion that he was Romanian.

"Ms. Marley, I saw in the paper of yesterday that Edward Theodoru passed away and I was wondering if you would be so kind as to give me directions to the location of the memorial service? The Alois Center gave me your name and phone number."

"Certainly," I said. "I'd be glad to. But may I ask first how you knew Ed?"

"Yes, Ms. Marley. I knew him ever since I came to Cincinnati back in the '70s," he said. "I am a jeweler and I met him through a mutual friend who was a R-r-romanian housekeeper."

"Oh," I said. "He talked about a Romanian jeweler frequently. That must be you."

"I assume so," he said.

"I'm glad we'll finally meet."

It felt so good to talk about Ed to a Romanian who'd known him for a long time.

"Ed was like a father to me," he continued. "Years ago I was working for a very unpleasant jeweler. I was furious with him all the time, and I wanted to quit but I decided to talk to Ed first. Ed listened to my complaints patiently, and then he firmly r-r-reminded me that I had no education, no training to do anything else. He told me that I must always r-r-remember that I had a nice job doing meaningful work in an air-conditioned shop wearing a clean white apron. He pointed out that if I quit I'd end up as a manual laborer in the freezing cold in the winter and the hellish heat of the summer, getting my hands filthy and breaking my back."

"That sounds exactly like something Ed would say," I said, smiling, remembering Ed's way of giving people wise advice.

“It was very hard to hear the bare truth,” he continued, “but I realized he was r-r-right. So I kept my mouth shut and every time I got mad at my boss, I just reminded myself of what Ed had told me. He saved me from making a *very* bad mistake. I will *never* forget that. Yes, Ed was always like a father to me.”

“You know, I’ll ask people to talk about Ed at the service tomorrow. I’d really like you to tell your story, if you don’t mind.”

“I do not know,” he said, hesitating. “I can try.” There was a moment of silence on the line before he continued softly. “I just do not know if I can tell that story without breaking down.”

He didn’t tell the story.

### ***Puff the Magic Dragon***

When we left Stuart’s office, the sun was out. It was an altogether gorgeous day, yet the warm sunny weather was in stark contrast to the overwhelming sadness I felt. Ed’s behavior that day had once again thrown the unpleasant truth in my face, but I refused to see it. Ed had deteriorated badly. There was little left of the life partner who had been with me for countless years, and even less of the lover I had known in the earliest days. My mind drifted back to happier times, to our vacation in 1976 at the Sea Pines Plantation on Hilton Head Island when we were still lovers. I was only 26 and Ed had just turned 63. I remembered that first pleasantly-warm summer evening when we were relaxing in our rented Harbour Town condo, listening to a folk singer strumming his guitar and serenading a group of little children sitting cross-legged under the gigantic harbor’s edge oak tree below our window. He sang *Puff the Magic Dragon* every night. I was captivated and always hummed along. Not that I didn’t like the other songs, too, but this one was special. Magical. And sad. Poor little Puff.

We had many beautiful vacations over the years, but this first one was the most wondrous of all. Ed paid my way. I was but a poor graduate student, not able to afford even one dinner on the island let alone an entire six-day vacation. I’d grown up in a poor family and had never been to *any* resort. That Ed took me there made me feel cherished.

Our condo, located right on the harbor across from the signature lighthouse, was magnificent. The dining room had large glass doors on one wall, looking out into the glorious harbor. The opposite wall boasted a massive mirror. So no matter on which side of the table you sat, you



saw the harbor filled with yachts from all over the world flying colorful flags as they rested in the glistening water, bobbing up and down rhythmically, the sunlight reflecting onto the ceiling in constantly swirling patterns.

Our bedroom had an enormous bed. Ed only had a twin bed in his apartment. While it was cozy and we slept perfectly well there, curled up warmly throughout the night, it was a treat to stretch out in such a big bed. It was the first time I'd ever slept in any bed larger than a twin. Drifting off to sleep that first night I felt as though I'd suddenly inherited a large sum of money.

We went to the beach every day. Ed's Eastern European skin tanned quickly, and by the third day he was deeply bronzed and even more handsome than usual, standing tall in the surf, waves washing over him. The fragrance of the pines was mesmerizing, mixed with the scents of the hot sand and ocean breeze.

In the evenings we strolled along the harbor, dining at a different restaurant each night, and then went back to our condo to enjoy a glass of fine wine, snuggle on the sofa, listen to the folk singer plucking his guitar as he sang, and talk into the wee hours of the morning.

As we were sipping an unusually fine Merlot one night, Ed told me about his experiences in Romania. He'd never shared anything about his past before.

"Back in the mid '60s," he said, lighting a cigarette and taking a deep drag, "after ten years of petitioning the damned communist regime, begging them to let me leave the country, I was finally granted permission to go."

I'd later learn the phrase 'communist regime' was not in Ed's vocabulary. The adjective was part and parcel of the only phrase he'd ever use: the '*damned* communist regime.'

"Ceaușescu was trying to show the West he wasn't a tyrant. And on top of that, they didn't really need me or any other lawyers in R-r-omania because the trials were farces anyway. But the main reason was that the Israeli government had agreed to pay Ceauseșcu \$10,000 for every Jew he allowed to leave."

I refilled our wine glasses and he continued.

"Ceaușescu's regime is considered to be the most brutal communist government *ever*, worse even than the Soviet Union. When I finally was able to leave R-r-omania I was only allowed to take today's equivalent

of a 'hunnerd' dollars and one suitcase full of clothing plus my elderly mother with her 'hunnerd' dollars and her suitcase."

He put out his cigarette and immediately lit another.

"I couldn't take any books, art or jewelry. I couldn't take my passport, college diplomas, or birth certificate. Not a single document that proved I even *existed*."

He paused, as if lost in his past, then continued.

"I left behind my home, my language, and my culture; *all* of my belongings and money; my profession, friends, relatives, and my way of life – all because I wanted to be a free man."

I wanted him to tell me more but he didn't want to talk about it anymore. He didn't like to talk about his past, and that night was no different. Instead he changed the subject and asked me to tell him about my mother.

"It isn't a very happy story," I said, refilling our wine glasses yet again. "Mother had a 'nervous breakdown' when I was five. She had depressions, delusions and hallucinations. The few existing medications at the time didn't help so she was given electroconvulsive therapy, or 'shock therapy,' as they called it back then. She was in a different world much of the time. Sometimes when we were in the kitchen she yelled out, 'Get down off my cupboard door!' I asked her who she was talking to and she'd say, 'That black devil sitting up there on my cupboard door.'"

"Oh, Kitty," Ed said. "That must have been for a small child frightening."

"Well, actually, it wasn't," I said, taking a sip of wine and moving closer to Ed on the sofa. "I remember trying to see that devil. I squinted and looked intently at each door. I thought there was something wrong with *me*. It was endlessly frustrating because I thought it would be fun to see a devil. Then there were the times she'd laugh uncontrollably. 'What's so funny?' I'd ask, confused because there was absolutely nothing happening in the room. 'The devil behind me is making me do it,' she'd say. I never saw that devil either."

I stretched out on the sofa and rested my head in Ed's lap.

"Other times she'd stare into space and appear to not even see me. I'd try my best to make her snap out of it. I'd tell her jokes, but they didn't break her trance. I even turned cartwheels once – I'd just learned how to do those in gym class – but nothing worked. It was as though I didn't

exist. Then sometimes she was very depressed. She'd lock herself in her bedroom and cry for what seemed like an eternity. Being shut out was intensely painful. And when my little friends came to play, sometimes she'd burst into the room heaving big sobs, tears rolling down her cheeks. I was mortified, and eventually stopped asking them to come play."

I leaned over to get a cigarette but found my pack was empty, so I took one of Ed's. I hated them. I smoked menthols; he smoked regulars. His tasted like dirty air.

"Mother suffered," I continued, "and I always wanted to take away her pain. I loved her so much, but she had her hands full with her depressions and psychoses. Years later she often said she was so sick back then that much of the time she didn't even know she *had* children."

I got up and went into the kitchen to get the box of Triscuits. When I came back I put some out and resumed my position on the sofa.

"My mom was so absent emotionally most of the time that my grandmother took over some of the mothering. She treated me like a little princess. But when I was six we moved far away and I saw her only twice a year – for summer vacation and at Christmas. I missed her so much, I constantly mailed her poems about how much I loved her. She kept them all her life. My parents found them among her papers when she died and gave them to me."

"What a sad story. You missed out on so much love and affection," Ed said. Then he reached for his wine glass and asked me to continue.

"There's not that much more to tell. As an undergraduate, I was obsessed with my mother's mental illness, and I asked everyone who knew her about it. My Aunt Alice was the only one with more information. She told me that mother had tried to commit suicide twice. I was sorry I asked. I was shocked and distraught over it for weeks."

"I understand you so well," Ed said.

He often said that, and I think he really *did* understand.

"Long after I'd left home, new medications became available to treat depression and psychosis, and she finally escaped the emotional hell she'd lived in for so many years."

Then I was the one who wanted to change the subject.

"What about *your* mother?" I asked.

"Well, she's living in a nursing home in Golf Manor," he said. "I brought her here with me from R-r-romania. Hardly any political

refugees did that. You simply didn't bring your aged parents to the West. When I told her I was leaving the country she cried every day and begged me to take her, too. I didn't know how I was going to support myself, let alone provide for her, but I couldn't bear to leave her behind. I couldn't stand seeing her cry and I knew I would suffer terribly without her so, no matter how impractical it was – financial troubles, language issues, her advanced age and all – I decided to bring her here anyway.

Looking back on it now I can see it was an idiotic decision, but at the time I didn't care. But to make things worse," he continued, "she insisted on bringing her gold wedding band. It was illegal to even possess gold then, let alone take it out of the country. We hid it underneath the lining of my suitcase. If they had found it we would have both ended up in jail."

I didn't know whether to praise him for his bravery or scold him for his poor judgment about bringing the ring. I decided to do neither.

"How is she doing?" I asked instead, putting some cheese on a Triscuit.

"Not so well. She lived with me at first, but eventually I had to put her in a nursing home. She'd started having accidents in bed and forgetting the stove to turn off. Things like that. I was afraid she'd burn down the apartment. It was one of the most excruciating decisions I ever had to make. I feel guilty every time I think about it, but I know I had no choice."

I didn't know then that someday I'd face the same agonizing decision about Ed.

"The elderly woman in that tiny picture frame in your bedroom – is that your mother?"

"Yes, it is."

"She's lovely," I said.

She *was* lovely, but had such a melancholy smile.

He never did take me to meet her. I'm not sure why. Maybe he thought she wouldn't approve of him having such a young girlfriend. I'll never know. But the fact that he brought her here from Romania earned him my highest admiration. He had strength of character when it really mattered. And he had courage few could match.

That night when we first shared our past lives, we fell asleep nestled together, listening to *Puff the Magic Dragon*. I couldn't have known then that the day would come when I'd hear *Puff* in my mind in a time of

tragic sorrow, and tears would flood my eyes as I remembered that time when we were happy and lighthearted, that time when the world was our playground.

### **You Signed a *What*?**

I was frantic when Ed didn't answer his phone. I thought something terrible must have happened because he never went out on his own anymore. I'd called John, the doorman at the Edgecliff, and he hadn't seen Ed all day. Just as I was getting ready to drive there to check on him, the phone rang.

It was Ed.

"Kitty!" he said excitedly. "You'll never guess what I did today!"

"Where the hell have you been?" I asked, turning off the TV. "I've been trying to reach you for hours. I've been worried sick about you."

"I was at Indian Creek."

I knew that Indian Creek was one of Cincinnati's premiere gathouse rental communities, but I had no idea how he'd gotten himself there, or why he'd wanted to go there in the first place.

"A bus came today and took on a tour of their place several Edgecliff r-r-residents and I went with them."

What he told me next made my jaw drop.

"I signed a lease for a three-bedroom apartment!"

"You *what*?"

"I signed a lease for an apartment."

I sat down on the sofa ('fell down' would be more like it), speechless.

*How could he do such a thing without even consulting me?*

"It's beautiful, Kitty. It has several bedrooms, some bathrooms, a living room and some other rooms."

He didn't seem to be remembering the rooms very well.

"And there is beautiful, marvelous landscaping outside the building," he continued. "And my apartment has an *outdoor* patio."

I wondered where else a patio would be if not outdoors, but my main concern was that I was pretty sure he couldn't afford this new apartment.

"Ed, why did you sign a lease? They can force you to pay it for twelve months even if you later change your mind."

“No, Kitty,” he said. “The lease is just a piece of paper. It’s meaningless.”

*And this from a former lawyer.*

I thought this brash decision was just another instance of Ed’s eccentric behavior. Only much later would I realize it was another sign of his growing dementia.

I felt certain moving to Indian Creek was going to be a calamity. They didn’t have a doorman and you had to press a number on the handset of your phone to let visitors in. He’d never learn that. Most of all, I was pretty sure he couldn’t afford the move from a one-bedroom at the Edgecliff to a three-bedroom, two-bath at Indian Creek. But he’d signed a damn lease. I had no idea how I was going to prevent the disaster that was bound to cause.

### **First Secret Revealed**

Ed had two carefully guarded secrets – his age and his financial status. I needed to find out about the latter in order to know if he could afford the new apartment. I’d found out his true age during the first year of our relationship back in 1975. My curiosity about his age had increased steadily as I wondered if he was younger or older than my 47-year-old father. I was hesitant to ask, because something told me he would lie about it anyway, and I wasn’t sure I really wanted to know. Nonetheless, shortly after he returned from a three-week summer trip to France, I casually asked him how old he was. He nonchalantly said he was 52, 27 years my senior.

In some ways I felt ridiculous being romantically involved with a man almost twice my age, a man *older* than my father to boot. But then Ed was the fourth man roughly that age with whom I’d been intimately involved in my short life. To me, men that age just seemed to exude romance and sexuality from every pore. And they really appreciated young women. Like Ed, they’d all treated me wonderfully – far better than any man my own age I’d dated. Besides, Ed was a ‘young’ 52. But I was fully aware that women romantically involved with older men almost always described them as ‘young for their age.’

One stormy day, with peals of thunder crashing all around and searing lightning brightening the otherwise dark sky, I’d gotten home from the university before Ed came home from shoe shopping (another obsession). As numerous thunder claps boomed, seemingly shaking the

apartment to its core, I'd shamelessly snooped around in his desk. I wasn't looking for anything specific, really. I just found Ed fascinating and suspected he might have secrets. And after unabashedly rifling through several boring documents, I was shocked when I actually found one. And it was a big one. According to the birth date listed in his passport he was 62, not 52. I sat there feeling dizzy, my mouth agape. In an instant I realized I was living with a senior citizen 15 years older than my father.

*Damn him.*

I threw the passport back in the drawer and sat down on the bed, fuming over this discovery. I was as angry that he'd lied to me as I was upset about the new even more astronomical age difference. I busied myself watching TV without really being able to focus and waited for him to come home. I hoped he'd be home soon and hadn't gotten waylaid in some luggage department.

"How the hell dare you lie to me about your age?" I demanded the instant he walked in the door.

"What are you talking about?"

"I found out your true age on your passport," I spat out disdainfully.

"How the hell dare *you* go through my personal papers?" he shot back, his voice louder than mine.

We went 'round and 'round like that until he eventually agreed to explain. He lit a cigarette, took a deep drag, and blew the smoke upward where it drifted in a series of little white puffs across the ceiling.

"*Little Kitty*," he said, "when I came to the U. S., I was already in my 50s and I knew I'd be quite a 'beet' older before I'd finish my PhD and start looking for a college teaching position. I was sure no university would want to hire someone that old. Since the R-r-romanian government didn't allow me to bring any documents attesting to my age, I simply ten years deducted on all my documents except my passport."

I was embarrassed about this colossal age difference, and not only when I first found out. There we were cavorting around like a couple of youngsters but he was almost old enough to be my *grandfather*, for God's sake. How was I supposed to introduce him to people? As my 'boyfriend?' That felt bizarre. My 'friend?' That didn't tell the whole story. There was no term to describe our relationship that didn't leave me feeling uncomfortable. When we were alone or with friends I felt

perfectly at ease. But I felt uncomfortable holding hands or walking arm in arm in public. I never *did* get used to it.

He, on the other hand, seemed proud as could be, showing his friends and colleagues that despite his age, he had the sexual prowess to capture and maintain the love and admiration of such a lovely and very young lady.

### **Second Secret Revealed**

And then nearly thirty years later, I was preparing to snoop again. All because Ed had gone and signed a damn lease for an apartment he was supposed to move into the following Friday. I needed to know if he could afford it, and I needed to know soon.

And there was another reason for my snooping that second time. I had a nagging worry that Irene was right when she said that Ed was showing signs of dementia. If so he'd have to go to a nursing home eventually. I knew the good places were expensive, often depleting people's resources. I'd want him in the best facility money could buy, and for that I needed to know how much he had.

Ed had been secretive about his finances all the time I'd known him, and I'd always assumed he had little money. After all, he'd come to the U. S. with little more than the shirt on his back and was a university professor. Everyone knows they don't earn much. Plus, he'd always been a horrible miser. Back in the 'good old days' when we went to fast food restaurants, they used to have little packets of mustard and catsup, and he always took some home. He also brought home extra paper napkins. And he saved the plastic containers from his Feta cheese. I once counted forty-five in the cabinet above the microwave. When I suggested he throw some out, he told me adamantly, "No, Kitty! I won't throw away even *one* of them."

When he retired he stopped buying new clothes. His pants were completely worn, tattered in places, and his undershorts were full of holes. Ed never bought new sheets or towels even though the ones he'd bought at thrift stores when he first came to the U. S. were threadbare. He wouldn't let me buy new ones either. Once I did, but he made me return them, saying he didn't need them; that his were perfectly fine. Actually, that was another one of his quirks. He *hated* getting gifts and made everyone who bought him one return it.



I knocked on his apartment door, and when there was no answer, I let myself in. It wasn't unusual for him not to answer the door because he was practically deaf and didn't hear people knocking. I smelled burnt food and found an unfinished container of blackened Stouffer's meatloaf on the kitchen table. *Yuck. How unappetizing.* A water glass half filled with Scotch mysteriously sat next to it. I was always surprised when I found an unfinished glass of booze. Usually he finished every drop. I wandered through the apartment looking for him. I heard the shower running, which told me it would be safe to start my exploration. It always took him around forty-five minutes to shower and shave – or 'shave myself' as he called it.

Knowing he'd be apoplectic if he caught me going through his papers, I nervously walked into his bedroom, pulled out the tan metal folding chair and sat down at his desk. The top of the desk was covered with papers – unpaid bills, sections from recent editions of the *New York Times*, two issues of the *Times Literary* 'Soop-lay-mow,' and a reprint of a scholarly article one of his colleagues had just published. I found nothing of interest in the desk drawers. I wasn't surprised. I was sure any information about his financial status was well hidden.

Next I started looking through the banker's boxes in his closet. Three were sitting on the floor next to ten neatly-lined up pairs of shoes, only one of which he wore anymore. There were three more boxes precariously balanced on the shallow top shelf. Before starting to delve through the boxes I returned to the bathroom to check if the water was still running. Since he shaved after his shower, I felt confident I still had time, but who knew – he just might skip 'shaving himself.' Sometimes he did that.

*God, what a disaster that would be.*

Nonetheless, I returned to the bedroom and continued my search. The box on the left contained brittle yellowed *New York Times* clippings – articles he must have stored with the intention of reading them some day. Or maybe he read them and kept them just for sentimental reasons. I glanced at a few and found they were either editorials or news stories about significant world events. The second box held neatly-stacked bills from Cincinnati Bell, CG&E, Visa, Master Card and Time Warner, along with several stacks of doctor bills and more than a dozen boxes of cancelled checks.

I was putting my hopes on the third box because the ones on the shelf would be awkward to replace quickly if he came out of the bathroom unexpectedly. So I opened it and found a large envelope filled with bank statements. There were also several bundles of letters, tied with little magenta ribbons, from his former wife, Charlotte. I was curious about the letters but didn't have time to read them. I couldn't have anyway. They were all in Romanian.

That box also contained another large envelope bulging at the seams. I opened it and found it contained numerous financial statements labeled 'Legacy Treasury Direct.' It sounded like some type of government investment. The statements weren't in any particular order so I quickly sorted through them, which made me nervous and wasted precious time. Finally I found the most recent. It showed a balance of \$453,000.

I sat back on my heels, scrutinizing the paper to make sure I was counting the right number of zeros.

I had.

My hands started shaking.

Then I heaved a sigh of relief and put the folder back in its hiding place and replaced the lid on the box. Then I walked straight to the fridge, got myself a Diet Coke, and sat down at the dining room table. I was still sitting there nervously twenty minutes later when Ed walked in wearing nothing but his underwear.

"Oh, Kitty. I'm delighted to see you!"

*If he only knew.*

Later that day back at my little house, which my mother always referred to as a 'doll house' because it was so tiny and cute, I stretched out on the sofa and wondered where he had gotten all that money. He had come here from Romania with nothing, then went to graduate school for a few years while working at menial jobs before becoming a professor at Northern Kentucky University and UC's Evening College. He only taught a few years before retiring. He told me many times the most he ever earned was \$27,000. A little quick math told me that even if he saved every penny he ever earned and made ten percent interest on it, it wouldn't have been anything near that much. Much later I asked his lawyer if he knew where the money had come from, but he had no idea either.

I was amused by how poor this man had acted over the years. Rather than bring home paper napkins from restaurants, he could have invested

heavily in the companies that made them. Instead of wearing underwear with holes, he could have bought enough shorts to wear a new pair every day and never miss the money.

I could only assume Ed's stinginess came from having endured years of poverty, first in Romania under the communist regime, then as a penniless political refugee in the U. S. His spending habits resembled those of Americans who had lived through the Great Depression. Even later, when their finances became solid again, many were careful with every penny, often able to save substantial sums of money.

I never did find out how Ed had come into his money. But that night I was relieved, knowing he could afford the new apartment. I also knew that, if need be, he'd be able to pay for the best nursing home anywhere. I just hoped he'd never need to use it for that.

### **The Tragic Truth**

The morning of the move to Indian Creek was filled with Ed yelling, "Kitty, come here!" and "Kitty, where *are* you?" or "Kitty, I need you in here *r-r-right now!*" as well as just plain "*Kitty!*"

Ed was extremely agitated as the four movers transferred his belongings from the Edgecliff into his new apartment. The crew was quite colorful. They were all wearing jeans and identical pine green tee shirts bearing the company name in big white letters. The leader was the owner's son, John. A strapping young man, he was at least 6' 2" and around 280 pounds. He had a dark brown crew cut and a short brown beard. He was the silent type but when he did speak, the others hustled. Darrell, his straight blond hair falling almost to his shoulders, was a tad effeminate. He assumed the job of unpacking and putting away the kitchen items, which he did with great care, arranging everything just so. Mario was middle-aged man with a big belly. His name and facial features indicated he was probably from an Italian family, but I didn't ask him. The fourth one was Guy, an average-looking young man, rather nondescript except for a tattoo on his right forearm spelling 'Lucy.' He smelled of smoke so I asked him for one, which he readily produced. I still had one occasionally.

They brought in Ed's belongings at lightening speed and unpacked everything efficiently. We'd paid them extra to unpack. God only knew I didn't have the time to do it.

“Kitty! Come here r-r-right now and tell these two men where to put the sofa!” Ed yelled, sitting in his recliner, which I’d requested they move in first so he’d have a comfortable place to sit as the men worked.

This was the third time he’d yelled for me when I was in another room following one of his prior instructions, telling the other two movers where to put something else. I couldn’t take it any more.

“Ed,” I screamed back, “I CAN’T! I’m in the bedroom showing them where to put the dresser, for God’s sake. Don’t you get it? I can’t be in two places at once.”

I was immediately ashamed of myself for yelling at him like that. Given his confusion, for which I still didn’t have a name or explanation, this was probably the most stressful experience he was going through since he’d come to the U. S. He must have felt frantic and helpless as his treasured possessions were being moved so quickly into this strange new place. I felt sorry for him, but at the same time I thought I was going to lose *my* mind before everything was unloaded, unpacked and put away.

And that was just the beginning.

I had hoped against hope Ed would adjust to his new apartment, but as I’d feared, he began having problems immediately. At the Edgecliff everything had been familiar, deeply ingrained in his mind after almost forty years of living there. At Indian Creek everything was new. His confusion became more pronounced; his memory problems more obvious. He couldn’t adjust to even the smallest changes. The new place had a different cable company and he never quite figured out how to operate his TV. He’d sometimes push a wrong button on his new remote and lose his cable connection altogether. I tried talking him through the process to fix it over the phone many times, but he just couldn’t get it. I’d always have to drive out and do it myself.

The method for letting visitors into the building was a challenge, too. He had to press the number ‘five’ on his phone’s handset to unlock the main door. I wrote down the instructions, and we practiced and practiced. He never did get the hang of it, so every time someone was coming to visit, I had to drive out to make sure his guest could get in. I became more deflated with each simple task he couldn’t learn.

His drinking didn’t make things any easier. I knew how much vodka he drank because I bought it for him. I know I shouldn’t have, but I knew he’d just call Mr. Ellington to drive him to the mall to buy it. Mr. Ellington would have dropped him off and come back later to pick him

up. I was terrified Ed that in the interim Ed would get lost in the mall. As bad as it was to buy the booze for him, I considered it definitely the lesser of two evils.

All things considered, I felt like a mother taking care of a little toddler, but the circumstances were bizarre because this mother and toddler didn't live in the same house. Just imagine a two-year-old living alone in a three-bedroom apartment, his mother coming to see him only once or twice a day.

I was alarmed and watched helplessly as Ed declined dramatically from day to day, becoming ever more confused. Forget about not being able to drive. It was at this time that he didn't even remember he owned a car, which I'd decided to just leave in the garage at the Edgecliff. He wandered around his apartment – often naked – until he happened upon the room he was looking for. I started wondering if he needed to go to a nursing home, but fought tenaciously to keep that idea at bay.

*He just moved there for God's sake. I can't move him again so soon.*

Then one evening Ed called me in a panic because he couldn't find his scissors.

"Go look in your kitchen," I suggested.

That's where he kept them.

"Kitchen? What's a kitchen? I don't have a kitchen."

A lightning bolt seemed to hit me.

*This can't be happening. He can't be this confused.*

"You know, Ed. Where your stove is."

"My stove?"

He didn't know 'stove' any more than he knew 'kitchen.'

"Your *kitchen*, Ed. Where your refrigerator is."

*Silence.*

"Ed, the refrigerator. You know – where you keep your food cold. Your refrigerator is in your *kitchen*."

*More silence.*

"Oh, you're right," he finally said. "How silly of me. I do have a kitchen, but it only has clothes and shoes in it."

"No, Ed. That's your closet. I'm talking about your *kitchen*."

After awhile I got off the phone without being able to help him find his kitchen, let alone the scissors he'd been looking for when he first called.

My hands were shaking, my vision blurred. I felt weak and dizzy as I finally realized the tragic truth.

Ed was demented.

## **Chapter 5: At Least It's Not Alzheimer's! (2005)**

### **The Appointment**

When I sat down and thought about it the next day, I realized that Ed's symptoms were so clear, anyone in his right mind would have realized years earlier that he was gradually dementing. Perhaps I'd been too busy taking care of him, too distraught worrying about him, and too consumed with seeking solutions to each problem to be able to sit quietly and reflect on his overall mental status. Looking back, I condemn myself for having let him live alone when I should have realized that living alone was endangering his very life.

But when he no longer knew what a kitchen was I couldn't keep denying the obvious. My heart sank as it became perfectly clear. He could no longer live alone. And he couldn't live with me either. I had a full-time job that required me to work long hours on evenings and weekends. I'd never have the time to take care of him, and if I did take the time, I'd never get my work finished and would end up losing my job. And there was no one else with whom he could live either. I was going to have to turn right around and move him again, this time to a place where people would look after him day and night.

Many people feel putting their loved one in a facility is a horrible thing to do, but I was convinced that in this situation it was the most loving thing to do. He desperately needed so much more care than I could provide. This man I had loved for nearly thirty years had become so demented that it was going to 'take a village' to care for him.

He needed doctors, nurses, aides, laundresses, cooks, dishwashers, and maintenance men. He needed an activity director, a dietician, and a social worker. And he needed those people to be available in shifts or on call twenty-four hours a day seven days a week. Most importantly he needed an administrator to train, coordinate and direct the efforts of all

those personnel. I could no longer continue filling some of those roles and driving him to people who could fill the others. Not while holding down a full-time job.

The only problem was going to be figuring out how to convince my deeply beloved strong-willed, fiercely-independent, heavy-drinking, stubborn Romanian that he had to go. I knew we were going to have a colossal clash of wills. I hoped I'd prevail, but I wasn't holding my breath.

I decided to enlist the help of Ed's internist, Dr. Bibler. Since Ed held Dr. Bibler in the highest regard, I figured if he told Ed he should go to a nursing home, maybe he'd listen. Because I was simply getting nowhere by myself. Every time I brought it up Ed said he'd die before he'd go to a nursing home and we'd have a bitter argument. I was exhausted.

So I called Dr. Bibler's office to make an appointment to talk to him about Ed's mental condition.

"I'm sorry but that's illegal. There's no way we can give you an appointment like that," Mary, the receptionist, said officiously.

"It *is* legal," I snapped back, sitting up straighter in my chair. "The patient is demented and I have Power of Attorney for him."

Ed had signed the Power of Attorney document several years earlier when he'd originally executed a Will, a Living Will, and the two Powers of Attorney. The Healthcare Power of Attorney gave me the authority to handle his health issues. The General Power of Attorney, however, was a different matter. That was the one that would give me control over his finances, and he wasn't about to do that. So he'd written up a document himself, which only gave me the authority to pay his monthly bills – nothing more. It wouldn't allow me to manage all his affairs. Fortunately, when the time came, Stuart persuaded him to sign a proper document. By then Ed was too demented to realize what powers he was giving me.

"I'm sorry, hon," Mary answered in an impertinent tone of voice. "It's still illegal because of HIPAA."

HIPAA, the Health Insurance Portability and Accountability Act, is a federal law that provides for the privacy of people's health data. Mary was partly right. Generally it would be illegal for Dr. Bibler to discuss Ed's health with me, but since Ed was mentally incompetent and I had Power of Attorney that changed everything.



"Mary," I said, about to lose my temper, "take down this message word for word and give it to Dr. Bibler. Let *him* decide if he'll see me."

Sure enough, the next day Mary called and sweetly told me I could have an appointment the following Tuesday. Ed would have been irate if he'd known I was doing that behind his back, but it had to be done.

I arrived early for my appointment. I always arrived early for appointments. If I wasn't early I considered myself late. I sat in the nearly empty waiting room, thumbing through an old copy of *Newsweek* that didn't interest me in the least, and praying that Dr. Bibler could help me get Ed into a facility.

### **Not the End of the World**

While waiting to see Dr. Bibler I was suddenly transported back to another waiting room when back in 1981 Ed and I were waiting for news about his eye. He was 68; I was 31. Our romantic relationship had ended three years earlier and we'd become closest friends.

"It isn't the end of the world," said the ophthalmologist as he closed the chart and looked at Ed, whose facial expression was a mixture of shock, fear, and despair.

We were sitting on old beat-up wooden chairs in a stark white antiseptic-smelling exam room. The counter surrounding the tiny sink held an oversized plastic model of the human eye neatly cut in half, exposing the inner workings of this exquisitely sensitive organ so critical to our lives. I could hardly believe what I was hearing. The doctor had just casually informed Ed that he had a tumor in his right eye and would have to have the eye removed. And he really thought that wasn't the end of the world?

Just thinking about Ed having his eye removed made me cringe. And the words 'tumor' and 'cancer' terrified me. I was distraught picturing Ed going through this ghastly ordeal, and I felt even more distressed when I suddenly realized that the cancer might already have spread to critical organs.

Sacrificing an eye wasn't a decision Ed would take lightly. The next day he decided to get a second opinion. His ophthalmologist readily agreed and referred him to a doctor in Philadelphia at the Wills Eye Hospital. Ed made an appointment to fly out a week later. He categorically stated that I couldn't go with him. He wouldn't tell me why. Nonetheless, I insisted. With his thick accent, hearing deficit, and

occasional difficulty understanding English, sometimes he didn't express himself clearly and at times he didn't fully understand others. I wanted to be there to help, to make sure he understood everything, to make sure everyone understood him. We argued about it intensely for several days and inevitably reached a stalemate. Finally I decided to discuss the issue with Marsha.

"What am I supposed to do?" I asked her, thoroughly frustrated.

She had a ready answer.

"Just buy a ticket. He can't buy all the seats on the plane."

I was amazed by the simplicity of her solution to the dilemma, and talked to Ed about it later that day.

"Kitty, if you don't let me go, I'm just going to buy a ticket for your flight and go anyway. You can't stop me," I said, expecting resistance or an outburst of anger. Anything but what was to follow.

"Well, Kitty, 'eef' you put it like that then I guess you can go," he said. And after a pause he continued. "I'll buy for both of us tickets so on the plane we can sit together."

He must have been pleased that I cared that much and at the same time surprised by my boldness, which was rather uncharacteristic of me.

The evening before the trip I helped Ed pack a little overnight bag, which, of course, took a lot longer than necessary.

When we were half finished he looked at me wistfully and said, "I wish I didn't have to 'make my luggages,' little Kitty."

For him packing for this trip was tantamount to putting his final affairs in order.

Finally he was satisfied with his selections and I went home to my tiny efficiency on Stratford Avenue to pack my own bag. I threw a toothbrush, toothpaste, deodorant, a hairbrush and a change of clothes into the only suitcase I owned and unceremoniously flung it into my car trunk. The next morning I drove to the Edgecliff to get Ed. He was supposed to be waiting in the lobby but he wasn't. Knowing him, this didn't surprise me. I assumed he was still packing, unpacking and repacking, so I went up to get him.

The scene would have been funny had the situation not been so grave. Sure enough, there he was, suitcase spread open on his little twin bed, a stack of neatly-folded shirts sitting on the pillow. I put my arm around his shoulder and talked to him quietly. I was able to calm him and

persuade him to choose *one* shirt to add to the underwear already in the suitcase, and soon we were off to the airport.

When we arrived in Philly we took a cab to the hospital, where we waited in a comfortable, almost cozy waiting room. After only about fifteen minutes, a nurse dressed in traditional whites, exuding an air of professionalism, called Ed's name. We followed her and the slightest aroma of a pleasant perfume into a large warmly-furnished exam room.

Soon a young doctor in a starched white coat confidently walked into the room. He had short blond hair and stunning blue-grey eyes, and introduced himself by a name I have long since forgotten. The irony was that he had completed his training at the UC ophthalmology residency program eight years before. So we'd traveled all that way to see a young physician trained by the very doctors who'd seen Ed in Cincinnati. Hardly the kind of 'international expert' we had hoped for. Nonetheless, he came with the highest recommendations.

His bedside manner was impressive. After studying Ed's medical records and examining him, he closed the chart, looked directly at Ed and spoke clearly, pausing *dramatically* between each sentence.

"I'm going to try to save your sight," he said.

"I'm going to try to save your eye," he continued.

"But *mostly* I'm going to try to save your life."

I was struck. What he said put things in perspective. It dramatically highlighted the fact that losing his eye wouldn't be the worst thing that could happen to Ed. He then examined Ed, discussed the enucleation procedure in detail and told us about some cutting-edge alternatives.

"The only danger with these other treatments is the slight possibility that the cancer will return and spread elsewhere in your body."

Ed left promising to weigh his options. He didn't think for very long. On the way home he decided to get rid of the eye and never have to worry about the cancer again – assuming it hadn't already spread. The grim decision made, all that was left was returning to Cincinnati and acting on it.

I remember the details of the eye surgery two weeks later as if it were yesterday. The letter from Holmes Hospital looked menacing. It sat on the kitchen table as though daring us to open it. So Ed did with trembling hands, as always, and read the two-line missive. Then with a dismal facial expression he passed it to me. It stated very simply that he was scheduled for enucleation on Monday, March 30 at 7:00 AM and

that he should check into the hospital by 3:00 PM on Sunday, March 29. I wished they'd added something personal such as "We're really sorry about this," or "We wish you the best of luck," but of course that was silly.

I took Ed and his little bag to the hospital at exactly 3:00 PM on the 29<sup>th</sup>. The packing had been especially difficult. Ed felt that 'making his luggage' was synonymous with putting his final affairs in order. Again.

As we drove to the hospital, frightful storm clouds loomed overhead and bolts of lightning periodically lightened the sky with jagged bursts of electrified whiteness. Reverberating thunder crashed down with a suddenness and intensity that caught us off guard and made us wince each time. The blinding rain, coming down sideways, forced me to drive more slowly and made us both feel especially somber. When we finally arrived, Ed registered and I took his arm as we walked to his room. The man who would be his roommate looked quite ill. His face was red and he coughed almost constantly. He told us he was scheduled for heart surgery the next morning.

After an hour or so, two residents came by to complete some paperwork. I left a couple of hours later, feeling thoroughly alone, eyes glistening, hands grasping the steering wheel tightly. I tossed and turned that night, waking up several times and checking the clock. People always say, "I wish it were me instead of him," and now I know that some of them really do mean it. That night I sure did.

As with most difficult things, anticipation is far worse than the thing itself. This was no different. The surgery went well. When they brought Ed down from recovery and gracefully tucked him into his bed, wearing a blue and white flowered hospital gown, he was groggy but didn't appear to be in pain. He had an IV attached to one arm and a very large bandage over his right eye.

When he became more alert I tried to get him to eat something. Dietary had sent in some chicken noodle soup in a little dark brown ceramic bowl. I took a spoonful to test the temperature and discovered it was barely warm. It looked like dishwater and had only five noodles in it. Honest. I counted them. And there was only one tiny square of what I presumed was chicken.

"Kitty, open your eye so you can see to eat your soup."

His 'left' eye was firmly closed.

“No. I will *not* open my eye,” he said, pulling his blanket further up on his chest.

“Why not?” I asked, getting up and walking over to sit on the edge of his bed.

“I am *not* opening my eye because it will hurt,” he said firmly.

“No it won’t. Just open it and you’ll see,” I said, not really sure if I was right.

As so often, the conversation continued in that manner, until I just fed him while he kept his eye closed. The picture of me spoon-feeding Ed while he stubbornly kept his eye closed is priceless and makes me smile even today. Hours later Ed finally acquiesced and opened the eye. As I had hoped, it didn’t hurt.

I went home that night but hardly slept, constantly worrying about Ed. When I arrived around 9:00 AM the next morning, he was ready to go. He was fully dressed, wearing the sport coat and tie he’d worn to the hospital the day he’d checked in, and was sitting on a chair in the hallway outside his room. He’d shaved, and as I neared I could smell the pleasant, familiar scent of his aftershave. He was calmly smoking a cigarette – this was before smoking in hospitals was forbidden – and was deeply engrossed in reading a newspaper story about the Hinckley assassination attempt on Reagan that happened the previous day.

“Hi, Kitty,” he said, smiling and blowing kisses my way when he saw me.

I was so shocked by his miraculous recovery I hardly knew what to say, so I just returned his greeting. No one would have guessed that little more than twenty-four hours ago that man had had an eye removed. He was back to normal in every respect except for that big bandage. I did have a good laugh on the way out of the hospital though. One of the nurses pulled me aside and told me that right before the surgery when they’d ask Ed to remove his dentures he’d said, “I can’t. They’re glued in!” Only Ed would say such a ridiculous thing. I took him home and in the hours and days that followed he never needed so much as an aspirin for pain.

### **The List**

As I was smiling to myself about Ed’s typically eccentric comment about his dentures, Dr. Bibler’s nurse called my name, bringing me back to the present. I followed her down a long corridor, passing a young

woman carrying a crying infant, into a cramped room into which the exam table had been fit at an odd angle. She closed the door and Dr. Bibler entered barely a minute later. He sat down, flipped open Ed's nearly two-inch thick chart and, while still reading it, asked, "What is it you wanted to discuss with me today, Dr. Marley?"

"I . . . Ed, I mean Dr. Theodoru . . . I'm here to talk about Dr. Theodoru."

Suddenly my tongue seemed tied. I felt like a traitor, talking about Ed's condition behind his back.

"I suspected as much, of course," Dr. Bibler said, finally looking up from Ed's chart. "But I wonder why you're here without him? Is he bedridden?"

"No it's not that at all. In fact, he seems in pretty good physical condition, given his age. Although he's been falling a lot, which worries me."

Dr. Biber looked at me expectantly.

So I took a deep breath and just said it out loud. "It's his mind. He's deteriorating. I think he's demented. I think he needs to go to a nursing home, but he won't even consider it. I was hoping you'd talk to him. He may listen to you."

"I see," Dr. Bibler nodded, "tell me about his falls first."

"Well, he's fallen five times in the past six months. Fortunately he hasn't hurt himself seriously, but I fear it's just a matter of time. He fell just yesterday and hit his head on the coffee table. He has a big lump on the side of his head."

"What do you think is causing his falls? Vision problems? Arthritis? General muscle weakness?"

"No, none of that, really..."

I hesitated. This really felt like treason now.

"If I may be perfectly honest, I think he's drinking so much that he loses his balance. And he's tripping over the edges of his area rugs. I can't convince him to drink less or get rid of the rugs."

"Area rugs can be treacherous," Dr. Bibler said, smiling at me. "And drinking alcohol, particularly too much of it, is not a healthy habit at any age."

Dr. Bibler put Ed's chart down and looked straight at me.

"But drinking and tripping alone are not proof of dementia."

"I know that," I agreed.

And then I gave him my well-organized typed list. I always made lists. Sometimes I even made a list of my lists. This particular list had examples of Ed's memory lapses, confusion and safety issues just during the month of April.

**Edward Theodoru, PhD, Mental Status Notes for April 2005**

April 2: Didn't know what Stouffer's frozen dinners were, even though he's eaten them for dinner every evening for years. He couldn't remember what they were until he saw them in the freezer.

April 8: Was confused about how to pay a bill. I had to go out to his apartment to show him. Was also confused about his return address. I had to tell him what it was and even then he made a mistake writing it down on an envelope.

April 10: Kept referring to the 5/3 Bank as "Kroger's" despite correcting him several times.

April 12: Had a phone conversation with someone, thinking he was talking to me. He wasn't, and to this day he doesn't know who it might have been instead.

April 13: Had no memory of Dr. Bracken, whom he's seen annually for the past 15 years. He remembered him the next day.

April 15: Begged me to come and find his pants for him. When I arrived they were on the bed right next to him.

April 18: Kept referring to his glasses as his watch.

April 19: Thought he was talking to his neighbor lady when he was in fact talking to me.

April 21: Called me at 3:45 AM with a minor question. I asked him if he knew what time it was. He said "3:45." I asked him not to call me in the middle of the night unless it's an emergency. He said he wasn't aware it was the middle of the night.

April 23: Removed his glasses to take some eye drops and it took him an hour to find them again. Couldn't remember the word "bathroom." Referred to his phone as "the computer."

April 24: Couldn't remember how to change the TV channel. I explained on the phone, but he couldn't understand. I had to go out to his apartment to show him.

April 25: Asked how to contact his building's doorman, but his new apartment does not have a doorman.

April 26: Has trouble finding specific rooms in his apartment and just wanders around until he happens upon the room he wants.

April 27: During a small fire in his building, he didn't react to the fire alarm, despite noticing thick smoke in the hallway. Said he didn't know the ringing alarm meant he should leave the building.

April 29: Looking through the register tape for his groceries, he asked what 'Starbucks' was and why it had such a funny name. Yet he's been buying Starbuck's coffee for years.

Dr. Bibler read the list carefully, then looked up at me over the rim of his glasses and simply said, "He has to go to a nursing home."

*Finally! Someone understands.*

"If I bring Ed to see you, will you tell him that?" I asked. Actually, 'begged' would be a better word. "He won't listen to me."

He took off his glasses, smiled and promised me he would. I nearly danced out of the room, confident this would settle the issue once and for all.

I stopped at the front desk and paid for the visit, which somehow didn't seem fair since I wasn't the one who was sick, and scheduled a time to bring Ed the following Monday.

On my way out I looked at my copy of the visit form. Dr. Bibler had recorded his diagnosis very clearly and simply: 'dementia.' Yet he never used the term with Ed. Maybe he didn't have the courage to tell Ed the truth. Maybe he thought Ed was too demented to understand it. Or maybe he thought Ed would get angry and there was no use getting into a big argument with a demented patient. I never asked him why he didn't tell Ed, but I always wondered.

I didn't tell Ed either. I didn't tell him because the diagnosis would have destroyed him. I just couldn't bring myself to do that. To this day I don't know if my decision was right or wrong, but it's the decision I made and I stuck with it to the bitter end. He'd always said that if he got Alzheimer's he'd commit suicide. I didn't think he'd actually do it, but I knew he'd suffer terribly.



**On His Terms**

"I am *not* getting a prosthesis," Ed had stubbornly insisted way back after his eye surgery. "I want to wear a black patch like Moshe Dayan and that shirt man on TV."

Ed liked to do things his way, always, and this pronouncement had Ed written all over it. The two men he referred to were fascinating, though in quite different ways. Moshe Dayan, symbol of the new state of Israel, was a true hero; the Hathaway shirt man was an instant advertising success exuding mystery and elegance. But I almost laughed out loud. What Ed hadn't figured into the equation was that wearing glasses over a black patch would look pretty silly. I didn't want him going around looking ridiculous. Even if *he* didn't care, I did. We argued about it for days.

"Just *try* it, Kitty," I said. "If you don't like it then don't wear it. Put it in a drawer and forget about it."

"No. I don't *want* one. I'll always be feeling it in my head. Besides," he whispered, "it will probably be very expensive."

"I'm sure your insurance will pay for it," I said, sitting down beside him on the sofa and taking a sip of my Diet Coke.

"No, they won't. I looked yesterday at my policy. For cosmetic things it does not pay."

"Kitty," I said bluntly, pointing my finger at the bandage, grateful it was covering the unpleasant bright red and empty orbit, "this is *not* a cosmetic issue. If they say it is then you just take off that bandage and walk into their office. That'll change their mind, believe me."

I knew what it looked like because I'd seen it when I removed the bandage after his surgery.

"I guarantee you they'll agree to pay for it immediately just so they won't have to look at you anymore. Anyway," I continued, holding his hands in mine, "why don't you call the insurance company and just *ask* them? Please? Just for me?"

He relented and called the next day and, as I'd predicted, they said it was covered. But stubborn as he was, he still refused. Initially, at least, Ed refused *everything* remotely related to medical treatment, especially if it were recommended by me or by a female nurse or physician. Men had a better chance of convincing him (which is precisely why I enlisted Dr. Bibler in the battle to get Ed to a nursing home). We argued about the prosthesis daily until I finally wore him down.

One of the larger optometrists downtown had a specialist who came in from San Diego once a month to handcraft prosthetic eyes. Dr. Lipins was a gregarious guy. His ruddy round face, white beard and big belly made him look almost like a Santa Claus. The day of Ed's appointment he was wearing a spotless white apron over a starched light blue dress shirt and black dress pants that were just a tad too short and revealed white socks. His charming accent indicated he must have been raised in the Deep South. "How y'all doin' this mornin'?" he greeted us, stuttering mildly when he spoke. But his stuttering didn't stop him from entertaining us with some amusing stories.

One patient, he began, spent a lot of time swimming, and his real eye would get red from the chlorine and since his fake eye didn't match he looked funny when he had been in the pool. So he had Mr. Lipins make him two prosthetic eyes – one for regular use and one with a reddish tint. Another one of his clients was a heavy drinker, who needed one prosthesis to match his real eye when he was sober and another for when he'd had too much to drink.

Lipins was quite an artist. We watched in awe as he was painting the prosthesis to match Ed's 'left' eye down to every tiny little vein. Occasionally he would hold it next to Ed's eye to compare. When we all agreed that the prosthesis matched the real eye exceptionally well, he said he'd fire it in his kiln overnight and we could pick it up the next morning.

When we returned, he showed us how to remove and reinsert the prosthesis so it could be cleaned periodically. I figured I'd better steel myself for the experience and pay close attention because with Ed's unsteady hands I knew I'd be the one doing it. I held my breath and practiced several times while Lipins watched to be sure I mastered it.

I must admit it took awhile for me to get used to the empty orbit, but eventually I became accustomed to being on 'private eye duty,' dropping everything and rushing to the rescue when the prosthesis got misaligned, which happened from time to time. Perhaps the Hathaway shirt man wore a black patch because he didn't have a nice young girl to help him with a prosthesis.

**An Emergency**

While I'd always found Ed's initial refusal to wear a prosthesis amusing and endearing, his stubborn refusal to take any advice from a woman could go too far.

Back in 1993, when we'd been together fifteen years, the tide had started to turn and, while Ed had taken care of me during our early years together, I was beginning to take care of him. He was 80 then and I was 43.

One evening Ed didn't answer the phone despite my numerous calls, so I went to the Edgecliff to check on him. I was horrified by what I found when Tom, the chubby maintenance man, let me into his apartment. Ed lay on his bedroom floor beside a small pool of urine. He was wearing only an undershirt, and was shivering violently.

Tom covered him with the blue wool blanket from the bed, then left, leaving me all alone to handle the emergency. I felt like a small child completely incompetent to handle that life and death situation. I had wanted Tom to stay and take charge, but he'd left so I had no choice; I had to spring into action.

Ed was conscious and when I took his temperature the thermometer soared to 104. I called 911 immediately. Four strapping paramedics headquartered at the fire station just around the corner stormed into the apartment less than three minutes later. They took Ed's vital signs and did a cursory check for broken bones, then wheeled in a threatening-looking gurney, preparing to transport him to University Hospital's Emergency Department. But then Ed did the craziest thing – even for him. He refused to go.

I begged and pleaded, to no avail. The paramedics urged him to go, but when they got the same response, they hoisted him into bed and left. Again, I felt like a child who had been deserted by grown ups who should have stayed to handle the situation. But they told me they couldn't force him to go.

I frantically called Dr. Bibler's office and reached Dr. Rose, the doctor on call, and explained the situation.

"It sounds like he may have a urinary tract infection," she said in an unusually low-pitched voice for a woman. "If he becomes septic it could be fatal. Let me talk to him. I can be very persuasive."

I gave Ed the receiver. They talked for about five minutes, his normally strong voice unusually weak.

"I understand you doctor," he said with great effort, "but I'm not prepared to go."

I wondered what would have to happen for him to be 'prepared.'

"If my temperature is in the morning still so high I will go to the hospital," he finally said.

I was terrified that might be too late and so, even though I already knew the answer would be "no," I took the phone from Ed and asked her the question anyway.

"Dr. Rose, can I have the paramedics take him against his will to save his life?"

"He seems mentally competent," she said, "so I'm afraid you can't."

"Are *you* telling *me*," I asked, looking at Ed, still shivering under his blanket, "that I will have to be the one to determine when he's become delirious and *then* call the paramedics, hoping it isn't too late?"

"Unfortunately, that's the case," she said matter-of-factly.

I couldn't believe it. I said "good-bye," then went out into the living room, pulled the cushions off the sofa and dragged them into the bedroom. I arranged them on the floor beside his bed and lay there all night, awake, checking periodically to see if his blanket was still moving up and down. At 6:00 AM the next morning I awakened him and told him to sit up so I could give him some water. That's when we discovered he was too weak to sit up, and he finally agreed to go to the hospital.

I called the paramedics again, and they arrived within minutes and wheeled him downstairs into the waiting ambulance. I was to follow in my car. But just as we were ready to leave the parking lot, I saw the weirdest thing. There was Ed, one paramedic on each side, holding him up under his arms, literally carrying him back into the building as he tried to walk, his shoes barely scraping the pavement. They later told me he had to urinate and *insisted* they take him to the little bathroom off the lobby. Only Ed would make such an outrageous demand.

His customary contentiousness continued at the hospital. A short blond female resident dressed in light blue scrubs came in to see him, closing the flowered privacy curtain behind her. I could tell this wasn't going to be pretty. She was a female physician, for God's sake. He'd never listen to anything she said.

"Dr. Theodore, I'm going to admit you," she said after examining him and making notes in his chart.

"No, you aren't," he said calmly from his supine position, certainly thinking that would be the end of it.

"You don't have any choice," she said. "It isn't up to you."

That was the worst thing she could have possibly said to him.

"We're in America!" he shouted, wagging his shaky finger in her face. "What do you mean 'I don't have any choice?' Neither you nor anyone else can against my will force me to be admitted to *any* hospital."

He was right, of course, but his decision could result in his death. I was desperate, and so I went to find the faculty preceptor, a Dr. Smith. Knowing Ed and all his quirks, I thought he might listen to a male physician. I explained the situation, and asked him to go talk to Ed. He agreed, and five minutes later appeared from behind the curtain.

"Dr. Theodore. Of *course* no one can force you to be admitted," he said after introducing himself. "But I'm afraid that if you go home now you may have a stroke or a heart attack – even today. If you stay here for a day or two we can stabilize you and you should be fine."

"Yes, doctor," Ed answered meekly. "Thank you, doctor. I will certainly take your advice and be admitted to the hospital."

That's all it took. A diplomatic male physician. Is it any wonder that, all those years later, I asked Dr. Bibler to the rescue when I needed him to convince Ed to go to a nursing home?

### **White Lies**

Taking the necessary steps to get Ed the care he needed required that I become a master of the art of deception. When I told him he had an appointment with Dr. Bibler he agreed to go *only* because I told him it was for a checkup. If he knew the real reason he never would have gone.

"Professor Theodoru," Dr. Bibler began.

Dr. Bibler was one of the few people who could pronounce Ed's last name correctly.

"How are you? I haven't seen you for awhile."

"Hello, Dr. 'Beeb-ler. I'm fine. As you know well, I am quite old, but I'm fine."

Dr. Bibler didn't know well how old Ed was. He'd lied on his medical forms.

"I'm glad to hear that," Dr. Bibler answered. "Have you had any falls recently?"

Ed thought a moment then answered, "Yes, I think I've fallen. I am not sure. But I think I hit my head."

"Let me take a look at it."

He got up and felt the side of Ed's head.

"Feels like quite a goose egg there," he said in a light-hearted manner.

"Yes, it does," Ed said, laughing artificially. He had no idea what having a goose egg meant.

"Have you had other falls?" Dr. Bibler continued.

"No. I can't remember any. Maybe. I'm not sure."

Which led Dr. Bibler to the next question.

"How's your memory been?"

"Oh, I think my memory is fine, Dr. 'Bee-bler.' I think I've fallen a couple of times, and I can't remember that, but my memory is fine. At least it's not Alzheimer's!"

He'd made that Alzheimer's comment at every single medical appointment he'd had the previous couple of years, no matter the reason for the appointment. He'd even said it to the podiatrist. He was clearly very concerned about it. I thought that perhaps deep down inside he had an inkling of what was happening to him, and my compassion for him was endless.

"Professor Theodoru," Dr. Bibler said, "I feel that at this point you'd do better living in a nursing home."

He closed the chart and looked directly at Ed.

"It seems you're having some memory problems and you're falling frequently. You'd be safer in an environment where people can help with everyday tasks, where people can clean and cook for you, entertain you, and tend to your medical needs."

He put his hand on Ed's knee.

"There are many fine facilities in this area. I would really like you to consider this."

He'd finished his speech without ever mentioning dementia or Alzheimer's.

Ed was silent for a moment. Then he cleared his throat.

"Dr. 'Bee-bler,'" he said, speaking formally and with a flourish of his hand. "If that is what you consider for me the best alternative, I will *certainly* follow your advice. With your years of experience, you know best undoubtedly and I appreciate and r-r-respect your judgment."

I was stunned. My little ruse had worked, and worked far more easily than I had dared to hope. I thought we were well on our way to a nursing home, but like so many times before, I never could have guessed what Ed would do next.

## **Chapter 6: The Search for a Nursing Home (August 2005)**

### **This Nursing Home Won't Do**

Since Ed had agreed to go to a nursing home, my next daunting task was to find a good one for him. I asked my friend Irene for recommendations, sure that, given her line of work, she'd know which facilities were best. She told me about three highly-regarded ones, but most warmly recommended the Alois Alzheimer Center, reputed to be one of the finest facilities anywhere. Unlike the other two, it specialized in dementia care. The first two would be convenient because one was literally on my way home from work and the other was five minutes from my house. Alois, whose stellar reputation I'd heard about before, would be an hour round trip. I decided to start with the ones closer to home.

I made an appointment at the first facility. Mary, the Director of Admissions, greeted me warmly, then led me to a cozy office off the main lobby. We sat down in comfortable upholstered chairs. Next to each was an end table holding a low-lit lamp. The room exuded tranquility. Mary, dressed conservatively in a navy blue suit, light blue blouse and medium heels, had a pleasant and calm facial expression, her demeanor suggesting she wasn't going to be the high-pressure salesperson I'd expected. I described Ed and explained why I felt he needed to be in a long-term care facility, all the while consulting the copious notes so typical of me. She took a few notes herself while I talked.

Next I told her how difficult it had been to get Ed to agree to a nursing home, and that I was concerned he'd change his mind any minute. I felt totally alone with this issue. Sitting in front of Mary, the enormity of the



situation caught up with me and I was suddenly overcome with emotion. I couldn't help it; I told Mary many details of my long relationship with Ed. I showed her a picture of us that I carried in my wallet. I wanted her to *care* about Ed. I wanted her to know how much I *loved* him. I wanted her to *feel* the depth of my sorrow about his mental deterioration. She said it sounded like a touching relationship, but made no other comments. Then I told her that he had come here as a penniless political refugee from Romania; that he'd sacrificed everything to come here; that he'd been incredibly brave and courageous to bring his mother with him. In retrospect I'm sure she had no interest in any of this, but I felt compelled to tell her anyway.

They didn't have a special floor for dementia residents, but tried to keep them in the same area. We decided to take a look at the resident rooms, and it was all downhill from there. The hallway was antiseptic. It was painted white, dimly lit, and the walls had little art or other decorations. I was crestfallen when I saw the rooms. They were extremely small, and none of them had private bathrooms. Many of the beds were unmade, and the mattresses were sagging so badly they looked like hand-me-downs from a second-rate motel. A few rooms were neat but most were messy and had clothing and personal items strewn about. All the furniture looked cheap and decades old. Residents were in various states of dress, many with disheveled hair. I couldn't imagine Ed living in such a place. And to make things worse, the rooms she showed me were doubles. Ed would never be happy living with a roommate. He'd always been the consummate loner, and both he and the roommate would be miserable.

"Do you have any private rooms by chance?" I asked.

"Yes, we do!" she answered exuberantly. "In fact, we actually have one available now."

She showed it to me with pride, but I was disheartened. It was incredibly tiny – about the size of the master bath in Ed's apartment.

"If you want it, let me know *immediately*, because some other people are considering it," she advised me.

"I will," I said, but as far as I was concerned the other people could have it.

As we toured the place I couldn't help but notice the distinct odor of human waste in some areas. I couldn't understand why they hadn't taken care of it. Even more unpleasant, if that was possible, was that

Mary, although warm and friendly with me, seemed distant from the residents. She didn't use the names of any we came across as we were touring, and ignored some of them altogether.

The other staff members didn't act very friendly to the residents either. A short and extremely thin resident dressed in grey sweat pants and a dingy white tee shirt hollered out that he wanted to go home. An aide told him curtly to be quiet. A little later another aide heaved a big sigh when a female resident in a wheelchair kept trying to get on the elevator. She told the woman to just stop it. Apparently detached and burned out, the aides seemed to be providing for the residents' physical needs only, completely ignoring their emotional needs.

Mary walked me back to the main door, where I thanked her and told her I'd think about it. But I knew I would not think about it, not for a moment. Ed would not live there.

I needed to find a place that would make an effort to understand Ed, to embrace him in all his cultural and personal idiosyncrasies. I would not allow that he'd have to live out the last few years of his life in a place where nobody cared who he was and where he came from. There had to be a better place in Cincinnati, and I was determined to find it.

### **Romanian Events**

Although he had left for good reasons and never wanted to return, Romania always was an important part of Ed's life and soul. And if that hadn't been clear before, it became evident the day the Romanian communist party fell. It was Christmas Day, 1989. He was 76 and I was 39. He was so excited when he called, his normal bass voice so high-pitched, his usual slow speech so fast, I could hardly understand a word he said. The only thing I did understand was his repeated command, "KITTY, TURN ON THE TV! TURN ON THE TV!" I turned on the TV. Images of Ceaușescu's dead body filled the screen. The Romanian dictator and his wife had not believed that the anti-government demonstrations would be successful, and had waited too long to escape the wrath of the people. When they tried to flee the city, they were tracked down, tried on the spot by a group of revolutionaries, sentenced to death, and executed. Thus had ended the life of one of the most brutal dictators the world had ever known. It was because of him that Ed had suffered untold persecution and it was because of him Ed had begged for

years to be allowed to leave his homeland even though he had to abandon everything and everyone he loved to do so.

Although before this event he couldn't go to visit Romania, Ed never lost touch with his friends. Around Christmas every year he shipped one-pound bags of coffee to several of them, because he remembered so vividly how near impossible it had been to find coffee anywhere for *any* amount of money. Only high-level communist party officials managed to get it. He'd sworn back then that if he *ever* got out of the country he'd send coffee to his friends every year. And he did. They adored him for it and knew he would never forget them.

He also sent medication, in particular a cardiac prescription drug, to a woman named Elena, who desperately needed it. The drug was not available in Romania, and even if it had been she couldn't have afforded it. But her doctor told her if she could somehow manage to get it, it would undoubtedly extend her life. She called Ed and he told her not to worry. That he would get it for her. Not only was the drug outrageously expensive even by U. S. standards, it was also illegal to have an American physician write the prescription in Elena's name without examining her. Ed didn't care. He found a willing doctor and he did it anyway. Every month until she passed away. After Ed's death I learned from a mutual acquaintance that Elena had been Ed's first love.

The Iron Curtain had fallen, and perhaps the need for coffee packages was over once and for all. And Ed started thinking maybe he'd be able to visit his homeland again, something he thought he'd die without being able to do.

That seemed like a good cause for celebration, and I decided to throw a surprise party for Ed and invited Marsha and Barb, a friend from work, to help me plan it.

Barb and I had become close during our regular Tuesday lunches. She was quite short with long unruly jet-black hair and nearly black eyes. She was married to an eccentric, portly, mustachioed Croatian much her senior. One of his more pronounced oddities was that he turned the heat off in their house during sub-zero winter nights even though it invariably resulted in frozen water pipes. He spent more on plumbers than he saved on gas bills. Our respective relationships with eccentric older Eastern European men added to the strong bond between us.

We made a revolutionary flag for the party. The Romanian flag had the coat of arms of the Romanian Socialist Republic in the center. But

the revolutionaries cut and even burned the coat of arms out of the flag, making what they called 'the flag with the hole.' We crafted our makeshift revolutionary flag from worn out tee shirts, burned a hole in the middle, glued it onto a dowel, and put it in silver gift wrap, adding a big red bow. Then with a flourish, we placed it in the center of my dining room table.

As arranged with Marsha and Barb, at six sharp Ed and I arrived at my house for the party. I'd picked him up because he didn't like to drive after dark. We entered and were greeted by the heavenly aroma of the pot roast I had simmering on the stove. Marsha and Barb were hiding in the kitchen. Ed and I sat down on the sofa and I comfortably leaned my body against his as we talked about the latest news from Romania and waited for the roast to finish cooking.

"Surprise!" Marsha and Barb yelled, running into the living room. Ed was startled. And confused about why we'd throw a party for him. So we explained, and as he began to understand, a smile formed on his face and he teared up.

"I am honored to be on this 'is-toric' occasion here with you ladies," he said in his most formal manner. "And I am 'hunnerd' times honored you are having just for me this celebration."

"Congratulations, Kitty. Now you're truly a free man. You could even go to visit Romania now."

A little later we sat down to eat. The delectable pot roast, its juicy meat surrounded by tender carrots, potatoes, and onions, was preceded by prodigious amounts of champagne and caviar. For dessert we had Pepperidge Farm Milanos, Ed's favorite cookies, and Graeter's double chocolate chip ice cream, Cincinnati's best, filled with its signature gigantic chunks of solid chocolate. More lively toasts and considerable clinking of fluted glasses followed.

Finally, it was time for evening's highlight – the presentation of the colors. Although Ed had been glued to his television since the 25<sup>th</sup> and had read the entire *New York Times* from front to back every day since, somehow he'd missed the detail of 'the flag with the hole,' so we had to explain that as well. For the second time that evening his eyes misted over. I later found that little flag when sorting through his belongings shortly after he died.

A year later, even though he was 77, Ed did make a trip to Romania, where he visited his few friends and relatives who were still alive.

Packing for the trip was the most excruciating ordeal of that for any trip he ever made. I worried about him the whole time he was gone. It was true that the dictator was dead, but I worried there could be others from the old regime who could possibly harm him. Needless to say, I was tremendously relieved when he made it back safe and sound.

### **What if You Had a Fire in Your Kitchen?**

Ed answered the knock on his door and found a pretty young lady in her mid 20s standing there. He smiled and gestured for her to enter. "Hello there! Oh! I'm so excited to *see* you again. How have you *been*? Come 'een'! Come 'een'!" he bid her.

Only thing was, Ed had never seen her before. That alone pretty much fulfilled the purpose of her visit. Kristi, Director of Admissions at the Alois Center, was there to evaluate Ed for placement, even though neither he nor I had yet visited the Center. That was a common practice of theirs, although it sometimes ended up that they evaluated patients who never moved to the Center.

I'd warned her I couldn't promise he'd even allow her in, let alone talk with her, so I was immensely relieved he was agreeable that day. Ed was oblivious to the real reason I'd arranged this interview. I'd told him she was a friend of mine who worked in a nursing home and she wanted to practice interviewing elderly people. That was just another of the white lies I had to tell him to get what I wanted and he needed. It was only because of his dementia that I had to do it and it was only because of his dementia that I could get away with it.

The apartment smelled of the toast he'd burned earlier that day. He still insisted on using the toaster even though I'd told him a hundred times not to. When the bread didn't get brown enough he turned the dial all the way up and it burned every time. He didn't even seem to notice it was burned, and happily spread his favorite apricot marmalade on it and ate it with pleasure.

Other than the smell, Ed and his apartment were reasonably presentable that afternoon. He was fully dressed, albeit in his 'house clothes,' and had his dentures and eye prosthesis in, which I'd come early to check. He sat in his recliner, which served as the centerpiece of the living room from which he watched his precious political talk shows. Kristi, her white summer dress flecked with little green flowers matching the freshness of the sunny and breezy late August day, took a seat on the

sofa near his chair. Not wanting to interfere, I sat at the far end of the sofa, planning to just observe.

She explained the real reason she was there. He didn't seem to understand, but he was in an excellent mood and readily agreed to talk with her. I assumed it was mostly because she was so young and pretty. He loved all young and pretty women.

I was relieved because just the week before he'd sent away the maintenance man who'd come to fix his toilet even though he'd called and asked him to fix it.

Kristi consulted the paper that was attached to a manila folder with a large paper clip, turned her body directly toward Ed, and began asking the usual questions, enunciating each word clearly and loudly.

"Can you tell me who's the President?"

"Boosh," he blurted out, grinning.

"Can you tell me what date it is today?"

He thought for a few seconds, then his head began to slowly shift downward as he simultaneously turned his left wrist inward a little.

*Well, I'd be damned! His mind isn't totally gone. He's alert enough to remember his little Timex has the date on it.*

That gave me some comfort. He stated the correct date and we all laughed about his cleverness.

"What state are we in?" she continued.

He appeared confused and looked at me.

"Sorry, Ed. You have to answer by yourself."

"I'm so sorry," he said, looking back toward Kristi. "I really can't remember. I think it may be Ohio. Or Cleveland."

"Okay," she said. "What country do we live in?"

"America!" he shouted with glee.

"That's right! Now, can you count backwards by sevens, starting at 100?"

He had a blank look on his face.

"Count how?"

"Backwards."

"I can count very well – in English and in R-r-romanian."

"Can you count backwards by sevens, starting at 100?" she repeated.

He looked at me again.

"I'm sorry but I can't help you, Ed."

"I don't understand the question," he told Kristi, sounding flustered.

"That's okay," she said. "Let's go on to the next question."

"Certainly!"

"Can you spell the word 'world' backwards?"

He thought a moment then answered, "w - o - r - l - d."

"That's spelling it forward, Ed. Can you spell it backwards – starting with the last letter?"

"Well," he answered, "the last letter is 'l'."

I hoped I wasn't looking disappointed.

She continued with her questions and wrote down everything he said.

"Ma-r-rie is such a good and dear old friend of mine," he told Kristi after one question.

"I think Marie loves you very much," she said quietly.

I was quite shocked by her perceptiveness and rather pleased that she acknowledged my love for Ed, but at the same time I was a little surprised she was saying something so intimate to two people she'd just met.

Kristi then asked the last question: "What would you do if you had a fire in your kitchen?"

Ed thought for a minute then a sly grin slowly appeared on his face. He stretched out his arm, pointed to me with his shaky finger and proudly announced, "I'd call *her*."

Kristi and I laughed, which made Ed laugh, too. But it was also sad. His mind could no longer tell him how to handle an emergency. The only solution to any problem he could think of was to call me.

How different had things been twenty-five years earlier, when a neurologist had given him a Mini-Mental Status Exam during a visit Ed had scheduled to find out if he had Parkinson's – which he didn't, of course. Back then I would never have believed that years later he'd be doing another such exam in which he'd perform so poorly. The contrast was so striking, so poignant.

We were still lovers then. I'd been circling the apartment in my grungy gray sweats collecting three days worth of laundry from the floors, chairs and bed when Ed came home.

"Kitty," he'd said excitedly, "I'm just from Dr. Robert's office back. You will *never* guess what he did."

"What, Kitty?" I asked, walking into the kitchen and dropping down onto one of the little green wooden folding chairs. From the excitement in his voice I could tell this was going to be a good one.

“After doing a physical exam, he started asking me questions that were obviously designed to find out ‘eef’ I’m mentally competent,” he said, joining me at the table.

I burst into laughter because Ed was sharper than anyone I’d ever known. There was no need to test him to see ‘eef’ that was true.

“I had a lot of fun with him,” Ed continued. “First he asked me ‘eef’ I know who’s the President. I said, ‘*Unfortunately*, it’s Carter!’ Next he asked me to name going backwards the presidents. I answered perfectly, of course, except I decided all the democrats to leave out! Then he told me to remember three words: ‘boat, flag, and shoe.’ He said he’d ask me to repeat those words in the visit later.”

Ed started laughing.

“Only thing is, Dr. Roberts forgot to ask me those words again. Dr. Roberts should make an appointment to see himself.”

I laughed out loud and realized I’d just witnessed Ed’s playful side – something most people never got to see.

### **This Nursing Home Won’t Do Either**

I went back to investigating nursing homes for Ed. ‘Miss Fashion Model,’ as I immediately dubbed her, the Director of Admissions at the second nursing home Irene had recommended, had the unmistakable air of a prima donna. Rosemary was her actual name and she greeted me somewhat coldly in the fancy lobby. The facility was home to many wealthy Cincinnatians, and I felt out of place in my standard jeans and tee shirt. Rosemary was at least 5’ 9”. With her height and facial expression, she was both literally and figuratively looking down at me. She probably thought I didn’t have enough money to put my loved one there, so I told her plainly that Ed had half a million dollars. She didn’t seem impressed.

We sat down on one of the fancy sofas in the fancy lobby, whose walls were adorned with copies of several Renaissance paintings. Having delved into a little art history in conjunction with my musicology studies, I recognized most of them. They included Bellini’s *Agony in the Garden*, and *Bacchus and Ariadne* by Titian. I had seen the originals when I lived in Italy, and would much rather have taken a trip down memory lane than concentrate on what Rosemary was telling me. There were also a couple of more popular paintings – Leonardo da Vinci’s *Mona Lisa* and *The Last Supper*.



Rosemary gave me a well-rehearsed sales pitch, then handed me fancy marketing materials. When we toured what I expected would be the fancy resident rooms, I was appalled to discover that they were even smaller and more depressing than the ones I'd seen at the other fancy place. They were also messier and the smell was stronger. And the staff members seemed like clones of those at the first facility.

"Can you help me put my shoes on?" asked a barefoot female resident wearing only a worn-out light green terry cloth bathrobe that was too short for her.

"Go find an aide," Rosemary answered, seeming embarrassed to have been addressed by a resident while she was giving a tour.

"Go back to your room and wait for lunch," an aide commanded a male resident who was pacing the floor and actually looked too young to be in a nursing home.

"Thank you so much, Rosemary," I said when we finished the tour. Then I turned and left without even asking about prices.

Any place that spends more money on the lobby than the residents' rooms does not have the right priorities. I couldn't and wouldn't put Ed any place where he'd be treated this coldly. No one should ever be subjected to such cold treatment – it's humiliating, and thus completely unacceptable.

### **The Love Letter**

I remember to this day how strongly Ed reacted to what he perceived as humiliation, and I cringe imagining how he would have felt at this place. Back in 1991, we spent two glorious weeks in Northern Italy, visiting the magnificent cities of Milano, Venice, and Gardone (at Lake Garda). The weather was splendid, the intensely blue June skies hosting white fluffy clouds in constantly changing patterns that gently moved overhead but never quite covered the sun. The temperature hovered around the mid-seventies during the daytime, and we never needed so much as a light jacket in the evenings. Mild breezes grazed our faces as we walked for hours at a time. We filled ourselves with marvelous Northern Italian cuisine, the glorious aroma beckoning from every café and trattoria. I loved Italy and was tremendously grateful to Ed for taking me there, where we soaked up every smell, taste, sound and sight.

Although our relationship had been strictly platonic for some time by then, Ed and I stayed in the same room in every hotel, sharing the same

bed. What I didn't realize was that Ed wanted people to *think* we were romantically involved. I would learn the hard way. The concierge at Gardone, a guy named Ernesto, a short heavyset middle-aged man with thinning brown hair and a square-shaped face was flirting with me and I responded in kind without actually realizing I was flirting with him.

Ed was quietly fuming – he always quietly fumed when he felt dishonored and humiliated. I truly should have been aware of my own behavior and I should have known that in his old-fashioned ways, flirting with another man in his presence was an affront. Proud as he was, Ed was so irate that he broke up with me as soon as we returned home.

I hadn't meant to humiliate him. I loved Ed deeply and sent him what can only be described as a love letter. It was another item I found when clearing out his storage unit after his death. When I found it I stopped packing up his belongings and gingerly unfolded the small sheet of pink stationery, its once bold blue ink faded after so many years. Then with ever so slightly trembling hands, I read it as though for the first time.

Dear Ed,

You said you're ending this relationship for your benefit. You said it's best for you. I sincerely hope you're right because I love you and care about you very much and I want to know you are happy always. I want to thank you again for the beautiful bracelet and painting, which will always remind me of all the good times of our relationship.

And I want to thank you for all you have done for me, for the thousands of ways you helped me, for all you have meant to me. You were the best friend I ever had in my life, and you contributed enormously to my well being and happiness.

I will miss you very much and I'll always remember you and be thankful for having been close to you.

I wish you all the best. I shouldn't think I can't be replaced. I hope I will, because I want you to be happy. I hope you will be lucky enough to find someone who will be as good a friend to you as you were to me.

Love, Marie

There it was, my love for him declared in all its depth. Although when I wrote the letter I thought our relationship was over forever, the

breakup lasted all of two weeks. Ed unexpectedly appeared at my apartment and – what else? – invited me to ‘dee-ner.’

I closed my eyes and took a deep breath before tenderly placing the letter in my glove compartment. It is still there.

### **The Perfect Place**

The Alois Center was my last hope.

I arrived for my appointment at 1:00 PM. The sofa in the lobby was as comfortable as it looked. A grand piano placed slightly off-center reigned the room, welcoming visitors with promises of music and culture. That was something you didn’t often see in a long-term care facility, and I thought Ed would be impressed. A gorgeous floral arrangement sat on a side table, and oil paintings of Cincinnati landscapes graced the walls. A glass door at the far end of the lobby led to a beautiful garden filled with a wide variety of shrubs and vivid flowers, a walking path and a few umbrella tables.

While in the other facilities the residents seemed to be hidden so the lobbies could be marketing showcases, it was clear that residents there used the lobby as a part of their living space. Two men were sitting on the sofa across from me, their walkers parked in front of them. A thin short lady in green sweats was circling the room’s perimeter. Two women clad in dresses like my grandmother used to wear were sitting side by side on another sofa. Kneeling in front of them was a male nurse who looked like Tom Cruise, giving them medication. A grey-haired man in khakis and a golf shirt sitting in a chair was reading a magazine. As I was trying to decide if he was a visitor or a resident, another grey-haired gentleman approached the front door. When he couldn’t open the door he turned and headed straight for me.

“Can you please unlock that door?” he asked politely. “I have to go to the police station. A man here is poisoning me with milk juice.”

I told him I didn’t know how to open the door, which at that point was the truth. I later learned it had a time-release feature to make it more difficult for residents to sneak out unnoticed. So then he went up to the receptionist and asked her the same question.

“Don’t worry, John,” she said in a soothing voice, patting his arm. “I’ll take care of it. Don’t worry about a thing.”

*What a difference from the staff at the other places.*

The Alois Center opened in 1987. It was the first facility in the U. S. dedicated to the care, treatment and study of Alzheimer's disease. Over the years they'd received numerous national and state awards, and according to their marketing materials, 99% of families were satisfied overall with the care their loved ones received and would recommend the facility to others. I doubted that the other homes I'd visited could say anything remotely like that.

During the tour Kristi explained they had four distinct units, each offering a different level of care. As residents needed more care they were moved from one area to another. Each area had its own dining room, activity room, outdoor garden area, and walking path, so the residents could always be with others like themselves.

Kristi stressed that they focused on improving the residents' independence, ability to function, and quality of life through specially designed programs that created a sense of belonging, accomplishment, and fun. I was sure my serious-minded Ed would never have fun but I was touched that they would even try.

The units were in separate wings of the building. To enter or leave you had to punch in a code on a keypad outside the door.

*Damn! When Ed sees this he'll realize he'd be limited to just one area. He'll never agree.*

I decided to worry about that later.

The entire place, including the resident rooms, was beautiful and clean, exuding a sense of calm and warmth. I immediately noticed the lack of odor save the aroma of the recent lunch, some of which lingered in one of the dining rooms. It seemed that broccoli was involved. The Assisted Living area, where Ed would likely start out, resembled an elegant hotel more than a long-term care facility. To get there we traversed a cheerful sunroom that was home to vibrant chirping canaries in lovely birdcages. Those little creatures would certainly delight Ed. From the sunroom you could see out to that unit's graceful garden and walking path.

The unit per se was brightly illuminated thanks to multiple skylights. There was an attractive dining room and a homey living room. As Kristi led us down the hallway towards the individual resident rooms, a slim female resident slowly walked toward us, her quad cane moving in time with her stride.

"Who are you?" she demanded, staring at my waist.

“Emma, this is Marie,” Kristi said cheerfully. “She came to look at our place for a friend of hers who might come to live with us. Wouldn’t that be fun?”

“Oh, I thought she was my daughter,” she grumbled, turned and tottered off in the opposite direction.

I was sold. Kristi’s friendly banter showed me that here residents were treated with respect and care.

We strolled down the hall and peeked into a couple of rooms. They were very spacious, each with its own bathroom. Now *those* were rooms Ed could live in. I saw charming artwork, tapestry, and bright quilts on the walls. All the beds were made up with colorful bedspreads and nearly all the residents were fully clothed – no threadbare night-clothes here. Everyone’s hair looked nice and all the men were shaven.

And most of the rooms were empty.

“We try to keep the residents out in the common areas during the daytime,” Kristi explained. “We don’t *want* them staying in their rooms all day. It isn’t healthy for them mentally or physically.”

“Well, Ed is a life-long loner and I can tell you, he’ll stay in his room all the time.”

“We’ll certainly change that!” she said, laughing.

I let it go.

Kristi explained that the activity staff members arranged different entertainments every day for the residents at each level. I couldn’t for the life of me imagine Ed participating in *any* activity but thought it was nice for the other residents.

The staff – aides, nurses, dining room attendants and others – appeared patient and genuinely caring. I saw an aide in the Commons hugging a seemingly confused resident, and a nurse in the Courtyard holding hands and talking quietly with another. The staff members were calm, even with a man in the Terrace who was loud and angry, and a woman who was trying to sneak out the door. I was impressed; these employees just might have the patience to deal with Ed’s angry outbursts.

In my mind it was settled. This seemed like a superb place for someone you loved. When we finished the tour, I decided to come back with Ed the next day, and told Kristi he would move there.

How naïve I was.

**A Sudden Change of Plans**

"Kitty! Guess what!" I said. "Today I visited the most wonderful place for you to live and I'm taking you to see it tomorrow. You'll love it."

He was sitting in the kitchen eating 'Stouffer's Stuff' as he called it. It looked like lasagna, his favorite. Instead of vodka he was drinking a Heineken.

"Oh, I changed my mind," he said as calmly as if he were telling me he had decided not to watch *Face the Nation* that day. "I'm not moving."

I was dumbfounded.

"But Kitty," I gasped, sitting down in the little green wooden chair that screeched as I scooted it under the table. "Dr. Bibler told you that you should go to a nursing home and you told him you would."

"No, I never told him that. That's a fantasy of yours," he said without even looking up. "You are inventing that. You should be ashamed of yourself, Kitty."

I clenched my teeth, crossed my arms, and stared a hole through him. Then I decided to take a different approach.

"No. Don't you remember?" I said warmly, putting my hand on his, hoping to jog his memory. "We were just there two days ago. Dr. Bibler talked to you about your memory problems and your falls. He said he thought you'd be better off in a nursing home with aides and nurses and other people to help you. You said you'd follow his advice."

He took a big swig of beer then stared right back at me.

"I never said such a thing. I haven't seen Dr. 'Bee-bler' for two years. You're making that up. I told you – I will die before I go to any facility."

I started shouting. "You have to go. You promised. What the hell's wrong with you? You promised Dr. Bibler. Don't you remember?"

*Of course he doesn't remember. If he could remember such things I wouldn't be trying to get him into an institution in the first place.*

He shouted back louder than I.

"I have never talked to 'Dr. Bee-bler.'"

He took another swig of beer.

"Who is Dr. 'Bee-bler', anyway? I don't know anyone named Dr. 'Bee-bler.'"

I felt entirely lost.

**More White Lies**

It was just a matter of which one of us would wear down first. I nagged, begged, and pleaded with Ed for weeks. Finally, one day after an especially heated argument, he agreed to go look at the Alois Center.

I called Kristi and arranged for us to have a tour two hours later – hoping he wouldn't change his mind before then. He hadn't showered or 'shaved himself' yet so we had to hurry. I rushed him into the bathroom, at least as much as you could rush Ed to do anything, and then laid out his clothes while he showered and shaved. Then I helped him dress.

Surprisingly, he agreed to take the walker I'd gotten him two months earlier. Until then he had only been willing to use it sporadically, and that only at home. He looked nice in his navy slacks and cream-colored blazer. No one would have guessed that this refined-looking elderly gentleman didn't know his phone number and sometimes couldn't find his clothes. I helped him into the car and off we went.

As I had hoped, Ed was dazzled by the lobby, especially the grand piano. An apparently demented elderly man sat on a sofa staring at the floor. A young woman sitting beside him was trying to calm a lively redheaded toddler who was dancing around in front of them, a baby doll in her hand. A smile came to Ed's face the moment he saw the child. He got up and, steadily pushing his walker, approached her. Looking radiant, he exclaimed to the woman how beautiful the little girl was. I remembered hearing that animals and children reach Alzheimer's patients at levels others cannot.

Ed returned and was telling me how beautiful the child was when Kristi arrived, full of energy as always. He didn't appear to remember her from her visit at his apartment, but greeted her warmly and kissed her hand. I suggested we tour only the Assisted Living area, where Kristi planned to place him first, since touring the entire facility might be too taxing for him.

He loved everything as much as I had and exclaimed it was "Beautiful! Marvelous! Wonderful!" He was particularly drawn to the sunroom's canaries, as I'd expected, and stopped to whistle at them. He expressed delight at the dining room skylights. Much to my surprise he didn't comment on the keypad codes that opened the doors. His mind may not have been sharp enough any more to realize the implications. When we left he told Kristi he would consider moving there.

The next day we went back for another tour. He loved it even more than the first time. I was delighted but worried, with good reason, that something might go wrong. And sure enough, it did. As we were leaving he noticed the sign out front bearing the facility's name: 'Alois Alzheimer Center.' He immediately became irate.

"I won't move *here*," he said in an unusually angry voice. "I do *not* have Alzheimer's."

We sat down on a wooden park bench right outside the front door and began discussing it.

"Ed, that's just something they *specialize* in," I lied. "They have many residents who don't have Alzheimer's," I lied more.

In all honesty, though, I couldn't say I blamed him. It must all have been so frightening and confusing. But confusing or not, I needed to get him in there, so I left him sitting on the bench and went to find Kristi.

"He's objecting to the word 'Alzheimer's' on the sign," I said. "Can you do something – like tell him you're going to change the name?"

We discussed this at length, and finally she agreed to tell him she was going to *ask* the Director if they could change the name. Of course they wouldn't do it, but she could say in good faith she'd *ask*.

So Kristi joined us outside, sat down next to Ed and told him her little white lie. At first he resisted.

"No. I won't come here."

But after awhile he relented and said he would agree to live there if they changed the name. He didn't seem to make a distinction between "changing the name" and "asking about changing the name."

All this made me nervous. I had to get him in there before he changed his mind again. I didn't care how many damn lies I had to tell him.



## Chapter 7: Only If One of Us Is Dead (August 2005)

### Another Change of Plans

Ed's move was scheduled for the following day. I'd scheduled it that soon so I could get him there before he could change his mind yet again. He insisted on taking his eight bookcases and the nearly twelve hundred books that weighed them down. He said he wanted every single book with him until the day he died. I could understand that. Those books, arranged in an order only he understood, had been his lifelong companions. I had measured his room at the Alois Center, and there would be room for every single book. So that issue was settled.

Next we had to choose which furniture and art work he wanted in his new home. He made his selections as if he understood all his other belongings would go into storage, but I don't think he really comprehended that. Once that was done, all that was left was to pack his suitcase. I hoped we wouldn't have the usual difficulty 'making his luggages.'

The next morning I arrived around noon and found Ed naked except for his nylon navy socks, slid down around his ankles. He was sitting at the dining room table, an empty Heineken bottle pushed to the side, a glass of vodka directly in front of him.

"Let's pack some more, Kitty," I said, walking toward his favorite burgundy suitcase, spread open on the sofa just waiting for more clothes to be put in it.

"I'm not going," he announced matter-of-factly, taking a sip of vodka.

I wasn't prepared for that and exploded.

"What do you *mean*, you're not going?" I yelled, stomping into the dining room. Not exactly the way I should have reacted, but the stress of the situation was getting to me.

"It says it's an Alzheimer Center," he said casually. "I don't have Alzheimer's, so I'm not going."

It was odd, and not at all typical of the disease he claimed he didn't have. He couldn't recall the name of the urologist or internist he'd seen for fifteen years, but he remembered that sign he'd seen for the first time just the day before. Normally Alzheimer's patients have a far better long-term than short-term memory.

"Ed, I *told* you. That's just something they specialize in. Lots of people live there who don't have Alzheimer's," I lied. "Besides, they're going to change the name," I lied again, as I lied the last time I told him that. Apparently this particular lie hadn't been sufficiently persuasive.

He raised his voice. "I don't have Alzheimer's and I'm not going. I will die before I go there," he said. "Or anywhere else," he added.

He finished his vodka and refilled the glass.

"It's all arranged," I shouted. "You *have* to go. They're holding a room for you," I said, hovering over him.

He looked up at me and shouted even more loudly. "I do *not* have Alzheimer's. They are *not* a r-r-room holding for me. I never told them a r-r-room to hold for me."

I kept telling him he had to go and he kept saying he'd die first. Our voices got louder and louder. It was ridiculous.

Based on nearly thirty years of arguing with him, I could tell I'd lost the battle; at least for the day. I called the Center and told Kristi he had changed his mind. That I would certainly get him there eventually, one way or another, but not that very day. Then I called and cancelled the movers. After that I stared at Ed, told him I'd call him later, and left.

I immediately felt guilty for being so mean. The poor man couldn't remember the phone number he'd had for forty years. But I couldn't help it. I was exhausted from trying to hold down a full-time job *and* take care of Ed by myself when he should have been in a specialized facility with around the clock care.

On a typical day I got up at 5:00 AM, did some work for my job at home, then went out around 7:00 to check on Ed and give him his medicine. At 8:00 I'd go into the office, but he'd usually call and insist I come help him find his clothes, show him how to change the TV channel, or do some other task he *insisted* was an emergency. So I'd have to leave work and go do it. I often had to leave again later in the day to take him to one of his numerous doctor appointments, which could take

as long as three hours, including travel and waiting time. Then I'd go back to work. Around 5:00 I'd leave work for the day and go check on him and do other 'emergency' errands he'd called about. After that I'd do my own errands or just go home and rest. Around 8:00 PM I'd call to remind him to take his medicine. Sometimes he didn't answer the phone so I'd have to drive out to make sure he was okay. Some days I ended up going to his apartment as many as three times for one reason or another. Dead tired, I'd fall into bed by 11:00, then get up at 5:00 AM and do it all over again, day after day.

While taking care of Ed took up a huge amount of my time, the *real* problem was that he needed even more help than that. He *needed* to go somewhere where people could help him 24/7. He *had* to go to a nursing home. I just worried that I'd never be able to get him to go.

### **My Solemn Duty**

I found myself obsessing about the issue of what to do with Ed all hours of the day and night. I had trouble focusing on anything else at all. I found it impossible even to focus on my job, and was falling behind in my work.

At that point I began consulting almost daily with Clarissa Rentz, who was then the Director of Programs and Services at the Cincinnati Alzheimer's Association Chapter. I didn't know how this wonderful busy woman had the time or patience to talk to me so much, but she made time. I will *never* forget her help. She gave me an incredible amount of excellent advice and many useful suggestions as well as steady moral support. We talked about various facilities and strategies for getting Ed into one of them. We also discussed approaches for admitting Ed to the Alois Center against his will. Clarissa guided me along the tortuous path to institutionalizing Ed, but my mental health continued suffering and I still couldn't decide what to do.

Two paralyzing fears haunted me. One was that Ed would never speak to me again if I admitted him against his will. I was pretty sure of that one. I couldn't imagine he'd ever forgive me. The other was that he could very well die in his apartment from an illness or injury if I didn't admit him. There was no way I could win.

Finally I retained an attorney, Mark Reckman, who specialized in affairs of the elderly. Irene had given me his name.

“Marie,” he said during our first phone conference, “since you have Power of Attorney and Ed has a formal diagnosis of dementia from Dr. Bibler, it’s perfectly legal for you to admit him against his will. Ed legally appointed you to make decisions on his behalf should he become unable to make his own decisions. You must now fulfill your duty and make decisions for him.”

I then called Kristi to get her advice.

“It’s not uncommon to admit dementia patients who’d rather remain in their own homes,” she said gently. “It’s for Ed’s safety. It’s an act of love. It could save his life.”

“How do I do that?” I asked, sitting down at my desk, not at all ready for the answer.

“You tell him that you’re going for a drive together. Then you come here, bring him in, and simply leave without him. We’ll do the rest. Many people have had to admit loved ones this way.”

She said this as though it would be like dropping him off at Kroger’s to do his grocery shopping.

“What if he won’t get out of the car?” I asked, mindlessly bending a paper clip.

“You don’t have worry about that. We’ll be with you and Ed when you arrive to assist if necessary.”

“What will you do?” I asked, nervous and even a little nauseous.

“Whatever is necessary.”

I shuddered to think what that might entail. I closed my eyes, inhaled deeply and told her I’d think about it.

I then called all the people whose opinions I trusted. I called Marsha, Teresa, Barb and Irene. I called Dr. Warshaw, a faculty member in my department and the Medical Center’s Director of Geriatric Medicine. I talked to Stuart and Dr. Bibler. I called Mark Reckman *again*. I had an especially long phone conversation with my therapist, Rosa. I was on the phone so long with all these people my voice got hoarse. They all said essentially the same thing. That I was legally and morally obligated to take Ed to a long-term care facility – *soon* – even against his will if need be. I must ‘kidnap’ and imprison this poor man who’d relinquished everything to come to the U. S. just to be free. That was the most horrible thing I could imagine doing to him. I knew I was ethically obligated to get him there any way I could, but I didn’t know if I was emotionally capable of doing it.

**Between a Rock and a Hard Place**

In total frustration I finally asked my dear friend, Teresa, who'd moved from Cincinnati to Dayton a few years before, to come down for the weekend. I needed her advice and emotional support. Teresa excelled at emotional support.

I felt better already just seeing her shiny red Geo Metro pull up to the curb around noon the following Saturday morning. After she gave me a big hug and spent a good ten minutes petting and baby talking to Peter, we headed for our favorite restaurant, Jeckle's, in nearby Hyde Park. It was a clever play on words. We decided we'd go visit Ed after lunch so I called him to let him know we'd be there around 2:00 PM. I wanted to make sure he'd be presentable. I told him *three times* we'd be there at 2:00, and also told him that would be in *two* hours, in case his basic math skills were impaired that day and he couldn't figure out how much time he had to get showered, shaved and dressed.

Teresa was 5'2", two inches shorter than I. Her short blondish hair called attention to her pretty blue eyes, and she was one of the most photogenic people I ever knew.

We'd met around five years earlier when she was still living in Cincinnati. I'd been trying to find someone to tend to my unruly shrubs and garden beds, and a mutual friend recommended that I call Teresa, who was between jobs at the time and was doing odd jobs to support herself.

She showed up in clothes obviously intended for gardening – a stained gray tee shirt with a noticeable hole near the bottom hem, faded black jeans and disintegrating tennis shoes. No socks. She was quite a sight, especially compared to me. I was actually dressed *worse* that day. She cheerfully and energetically pulled weeds, trimmed hedges, and put down mulch for more than four hours in eighty-degree heat and the stifling Cincinnati humidity.

When I was writing out her check that evening, we started talking. There was something about Teresa that drew my attention. I couldn't say exactly what it was, but it made me curious, so I invited her to sit down and have some iced coffee with me. Turned out this young woman – she was twenty years younger than I – was highly educated. She had a bachelor's degree in International Studies from Kenyon College and a master's in Near- and Middle-East Area Studies from the School for Oriental and African Studies at the University of London,

where she'd studied for two years. She'd also spent her junior year of high school in Norway as a Rotary Exchange student. And if that wasn't interesting enough, she'd lived in Kazakhstan for her junior year abroad, *and* she'd been there during 1991 – 1992, when Kazakhstan declared its independence and the Soviet Union began to dissolve. I was surprised at her background and impressed by the languages she knew – Norwegian, Russian, and Kazakh. Those languages seemed mysterious and exotic to me. I'd never known anyone except Ed who could speak anything other than English, German or Romance languages.

As we were talking, I threw out a few tidbits of my own background. She seemed energized by talking with someone else who'd lived in a foreign country and could speak foreign languages, and she kept asking me questions about my year in Italy. The longer we talked, the more we discovered we had in common.

At that point in my life – I was 50 – I was making a conscious effort to develop new friendships, especially with younger people. Except for Marsha – and she'd moved to San Francisco by then – everyone I was *really* close to was over 70. I was acutely aware that if nothing changed, someday I'd be left with *no* friends. Teresa was young. But far more important, she was incredibly sweet and intelligent. So we began having lunch and just hanging out together frequently, and as the months and years went by, we developed a bond that continues to this day. There's something between us that's special and unique – an emotional closeness I've never had with anyone, not even Ed.

Once we arrived at Jeckle's for lunch that day we were seated at a table by the fireplace. In no time it became too warm and so I asked if we could move to another table.

*Oh my God! I'm acting like Ed!*

"You remember that night we had dinner here with Ed?" I asked Teresa after mulling over the menu.

"Remember?" she said, laughing. "As if I could ever *forget*."

As usual, and as I had forewarned Teresa at the time, we had changed tables twice.

*I must have picked it up from him.*

"But he was such a gentleman," she said, noticing her spoon was dirty and motioning for the waitress. "He even held out my chair for me."

During that dinner she and Ed had talked nonstop about their respective travels in various Soviet Union republics. My contribution had consisted of a single sentence.

"Ed," I'd said, "Teresa lived in Kazakhstan for a year when she was in college."

"Kazakhstan!" he exclaimed, his face beaming. "That's amazing! I was there one time. Did you ever go to Borovoye?" he then asked her. "Borovoye is beautiful like a fairy tale. They call it 'The 'Sveet-zair-lawnd' of Kazakhstan."

"Yes! I was *there!*" she said, smiling broadly. It seemed she hardly believed she was meeting someone else who'd been to that jewel of a city. "It's the most beautiful place I've *ever* visited."

The two of them went on and on, speaking endlessly of this city and that, one 'Stan' and another. I didn't know anything about *any* former republics, Soviet or otherwise, and couldn't join their discussion. I was bored stiff, but extremely pleased that Ed and Teresa were enjoying themselves and getting acquainted. By the end of the evening they seemed like old friends.

The next morning Ed called me, sounding altogether unhappy.

"You and Teresa monopolized the conversation last night," he said sternly. "You talked about things I didn't know anything about and I nearly fell asleep in my chair. You should have better *manners*, Kitty!"

I'd put down the phone in dismay, having no inkling this incredible mischaracterization of the dinner conversation was but one of many symptoms of his growing dementia.

So here I was again in the same restaurant, this time just with Teresa. It was time to bring her up to speed. I told her Dr. Bibler had officially diagnosed Ed with dementia. Then I described my visits to the Alois Center and told her Ed had changed his mind about going there twice. I followed that with a lengthy description about *my* mental state.

"I'm sad to hear that he's deteriorated so much," she said. "And just in the past month alone. But Marie, I'm really more concerned about *you*," she said, moving her menu to the side of the table. "Admitting him against his will is such a difficult and tricky thing to do. You're sort of damned if you do and damned if you don't."

"Yeah, I know," I said as the waitress arrived.

Teresa gave her the dirty spoon and she left to get another one.

"But I have to do something. I'm thinking more and more about 'kidnapping' him. But it will be the end of our relationship. He'll never speak to me again."

"It's possible, but somehow I think he'll either get over it or else forget all about it," Teresa said, reaching over to put her hand on mine. "I don't think Ed can stay by himself. If something were to happen to him, you'd never forgive yourself."

She was right. Nobody had put it quite so succinctly, but I knew she was absolutely right. Squeezing her hand tightly, I asked her a crucial question. One I wouldn't have asked anyone else I knew.

"Teresa, if I decide to take him against his will, would you come down that day and help me do it?"

I held my breath.

"Yes, of *course*, Marie. You don't even have to *ask* me that. Of course I'll help you. Just tell me when and I'll *be* here."

I exhaled and let go of her hand. I'd *known* she'd agree but felt better just hearing her say it.

The waitress came with a clean spoon and took our orders. I'd forgotten what I wanted and had to look at the menu again.

We spent the rest of the lunch talking about the logistics of kidnapping Ed. I had trouble concentrating, and more than once had to ask Teresa to repeat what she'd just said because my mind kept focusing on the potential dire consequences of taking Ed to Alois against his will.

After lunch we drove to Indian Creek. On the way I missed the entrance to I-71 and had to backtrack. I was just not with it that day.

Even though Ed knew we were coming, even though I'd told him three times, even though I'd specified how much time he'd have to get ready, despite all that he came to the door looking dreadful. He was barefoot and without his dentures and eye prosthesis. I was shocked to see his face missing these critical items, especially the prosthesis. But he didn't even seem to notice or care. And this from a man who used to dress so well, even at home. Teresa pretended she wasn't grossed out by seeing the empty orbit where his prosthesis was supposed to be, and waited patiently while Ed and I went into the bedroom to deal with the issues.

It seemed the prosthesis had come out during the night. He said he put it in a safe place but couldn't remember where. Fortunately, I just happened to see it in a little ceramic container by his bed and put it back



in for him. I was immensely relieved because it could have been lost forever in that big sprawling apartment. It would have been a nightmare to get a new one made given his behavior and state of mind at the time.

I found the dentures in a kitchen cabinet, where I looked only because he'd put them there once before.

His appearance was symptomatic of his poor state of mind that day. We stayed only for a short visit. When we left, Teresa gave Ed a big hug, and she was a good hugger. And when she left my house the next day she gave me an even bigger, longer hug. Although I was so glad she'd come, when I watched the Geo Metro pull away from the curb, I immediately began worrying again about what Ed would do if I took him to Alois against his will.

### **Damned If You Do, Damned If You Don't**

My brain felt like someone had put an electric mixer in it and turned it on high. I was afraid I was going to lose my mind – literally, *not* figuratively. Everyone was pressuring me to take Ed to Alois against his will, and I was just not quite ready to do it.

I knew he had to go to a facility and soon. His life was in danger. But if I did, he'd never speak to me again; he'd be alive but dead to me.

*Would our love really end that way?*

All I did was think about my dilemma. During lunches with friends, at work, and at home. *How can I do this to him?* My mind was constantly churning on the Ed issue, no matter where I was, who I was with, or what I was supposed to be doing. I didn't even pay attention during meetings at work. I sat at the large conference room table full of 'normal' people discussing 'normal' issues. I had no more interest than if they were reading the phone book aloud. All I did was think about Ed and the impasse I'd reached. That problem was the last miserable thought on my mind as I fell asleep every night and the first thought to enter my consciousness the moment I woke up each morning. I began to hate waking up. I wished I could just sleep all day.

In my mind I repeatedly listed all the reasons I should commit Ed. And the reasons I shouldn't. Finally, one morning over coffee in my little kitchen, I gathered the strength to do the right thing.

I decided I would move Ed against his will.

I set a date: August 8th. Only ten days away.

I was proud of myself for making the decision. And I was scared.

As moving day approached, my mental state started deteriorating. My fear that Ed would never speak to me again took on gigantic proportions. I felt like a criminal planning a shameful crime against someone I loved; against a vulnerable man who trusted me and depended on me. I was paralyzed. All I could do was eat, sleep and pace the floor. I stayed home all day; didn't even go to work one day. And then another day and another.

I sat in my little kitchen, where I'd made the decision to take Ed to the Alois Center, forehead resting on the table, my hands clasped around the back of my head. At that moment I faced the devastating truth.

I was not capable of doing it.

Over my own fierce objections, I canceled the move. I feared that Rosa, Stuart, Dr. Bibler, Kristi, my lawyer, and all my friends would think I was weak. And I *was* weak. But I canceled the move anyway. I felt like a failure.

Truth be told, I *was* a failure. And I couldn't imagine *any* solution to this horrible problem.

### **Who's Stopping Me?**

I was outright exhausted.

But I kept trying to convince Ed to go of his own free will. I was reminded of the struggle I'd had over getting him to stop driving. At that time I'd begged, pleaded, demanded, cried, cajoled, threatened and tried to reason with him. I decided to use that approach again. I bombarded him daily with efforts to get him to go. I imagined we'd have endless arguments about it and it would simply be a matter of who wore down first. I was younger. I thought that might help. I could hold out longer.

On one of so many days I walked in and sat down on the sofa, ready for the day's battle. He was sitting in his easy chair holding a glass of Scotch and watching 'Teem Russert' on *Meet the Press*.

"Ed, you really do need to go live at the nice Alois Center," I started with my usual opening.

"I will *never* 'leev' there," he said. "I don't have Alzheimer's."

"No, Kitty. That's just one of the many things they specialize in," I lied, as I lied about it every day.

I went to get some peach ice cream out of the fridge.

"Ed, turn off the TV so we can talk," I said when I returned.

"I'm not going there or anywhere else. I'm going to stay r-r-right here in my own apartment," he insisted as he obliged by reaching for the remote and pressing the power button. He'd finally learned which one it was.

"But Kitty, you really do need some help with cooking and cleaning," I said, plopping down on the sofa and setting my ice cream on the black wooden coffee table.

"No, I don't. I just heat up the 'Stouffer's Stuff' in the microwave," he said, his shaky finger pointing toward the kitchen, "and my apartment doesn't need cleaning. My apartment is all the time perfectly clean," he said.

*His apartment was all the time filthy dirty.*

"But you need someone to give you your medicine and be around in case you fall," I said, putting a gigantic spoonful of ice cream in my mouth. "What if you fall and can't get to the telephone to call for help? You could die. What then? Wouldn't it be much better to be at the Alois Center, where there's always a nurse available?"

"I don't care 'eef' I die. I will *never* go there," he said. "Leave me alone. I will die here in my own *very clean* apartment with my 'hunnerds' of books. I want every single book until the day I die."

"They said you can take your books. And there are lots of people around and fun activities every day," I said.

He finished his Scotch and crossed his arms. "I don't want people around. I want to be alone. And I don't want any activities. I'm telling you - I want to r-r-read all day. I have so much r-r-reading that I *have* to do. I have to r-r-read every day the newspaper and my books about literary criticism and literary 'teer-y.'"

That's how the argument went almost verbatim day after day for two weeks. And I could understand him. I, too, was a loner. I wouldn't want to 'leev' in one room in an institution. I, too, would want my solitude and independence. He wanted to be alone to read all day. I would want to be alone to write all day. But the truth was he had to go and it was my moral duty to get him there.

"Ed, you would be *much* better off at the Alois Center," I told him loudly in a moment of total frustration at the beginning of the third week.

"Who's stopping me from going there?" he suddenly demanded in a defiant tone of voice.

"No one's stopping you," I gasped once I recovered.

I couldn't believe what he'd just said and tried desperately to think how to capitalize on this obvious most demented moment.

"Why don't we go right now and visit?"

He cheerfully agreed, which astonished me. I called Kristi and arranged for a tour that very afternoon. He must have become so demented he'd forgotten his opposition.

We arrived at the Center and took the tour. When we were finished he kept saying it was "Wonderful! Marvelous! Superb!" and he would very seriously consider moving there. When we left he didn't notice the 'Alois Alzheimer Center' sign. For the rest of the day I talked to him about how wonderful the Center was, mentioning every little special detail. He agreed wholeheartedly. I had hope that this time I'd get him there before he could change his mind yet again.

The next morning he wanted to visit again. I arranged another instant tour, this time with the social worker, Ann.

"Wonderful! Marvelous! Superb!" he declared as we went around, just like the day before.

"Would you like to live here, Ed?" Ann asked.

"Yes! Definitely!"

"When would you like to move?" she asked, punching the numbers on the keypad to unlock the door to the lobby.

"As soon as *possible*," he answered loudly, accenting 'possible.' He continued, "*Tomorrow* even."

I looked at Ann. "I need to arrange for his furniture to be moved. That will take awhile," I said. "I'm terribly concerned that in the interim he'll change his mind. He did last time."

"Oh, Marie, don't worry about furniture," Ann said. "We have plenty in storage. We can fix up a room for him until you can get his moved. We could take care of everything by tomorrow. All you need to do is bring a few clothes and toiletries for him."

I had no idea they could do that.

I turned to Ed.

"Kitty, she says you can move here tomorrow. Do you want to do that?"

"Yes!"

"It's settled then. You'll move tomorrow."

As we continued walking I praised him repeatedly for his wise decision, trying to instill into his mind what was left of it.

When we got home he told me he was tired and wanted to take a nap. While he did that I discretely packed a few clothes and some basic toiletries in his navy-blue suitcase and put it in the trunk of my car. The less he actually saw, the better it would be. I didn't want him to be involved in 'making his luggages' for the move. When he got up I kept talking about his big, exciting move the next day, trying to help him remember he really wanted to go. After awhile I went home, worrying constantly that something would go wrong.

Turned out I was right to worry. I got a frantic call from Ed around 10:00 PM. I was already in bed and had to reach way over for the phone on my crowded nightstand, knocking a full glass of water off onto the floor.

"Kitty, I can't find my wallet," he cried out. "I've looked everywhere for hours. I can't find it," he said. He sounded like he was ready to burst into tears. "I'm r-r-ruined. I don't have my driver's license, I don't have my Northern Kentucky University ID card, I don't have my credit cards. I don't have my social security card. I can't move. I can't go *anywhere!* I'm not a person anymore. I'm a man without papers!"

I'd never heard him so distressed. I realized that because of his experience living in communist Romania, not having 'documents' was a true crisis for him. I felt for him and I was upset he was so distressed. I wished I could do something to make it go away. Most of all, though, I was incredibly pissed that he said he couldn't move. I sat up in bed and tried to calm him.

"Ed, this is not Romania. I can get all of your documents replaced in less than a week. Once I lost my wallet and I replaced everything in a few days," I said, exaggerating a bit.

He appeared not to have heard – or not to have understood – a word I said. I kept telling him I could replace everything quickly. Eventually, he both heard *and* understood me.

I was holding my breath as he asked incredulously, "You can?"

"Yes, I can. I promise. So you can move tomorrow and I'll get all the new documents for you next week."

"Well, okay. 'Eef' you promise," he said tentatively.

"I promise."

We got off the phone and I tried to sleep, but was awake most of the night, worrying about the next day and his move. At 5:00 AM I finally got up, puttered around the house, made coffee, took Peter out and tried to do a little work for my job, which turned out to be impossible. I turned on the TV and watched the news, but couldn't concentrate on that either, so I just showered and got dressed for the day ahead. It would be either wonderful or horrendous. Ed's very life – and my sanity – hung in the balance.

### **Only If One of Us Is Dead**

Turned out he never went to bed. That was what I discovered at 7:00 AM when I called Ed to wake him up. I reminded him he was moving to that wonderful place we'd looked at the day before. I held my breath, waiting for his response. Would he say he'd rather die than go there? I was relieved when he said he remembered and was looking forward to it. He didn't say anything about his wallet. I assumed he'd forgotten all about it.

*Nice thing about dementia.*

I drove to Indian Creek and let myself in. By then it was 8:00 AM. He was sitting at his dining room table with a Heineken. I told him to take a shower and shave, which he was still able to do by himself, although he was maddeningly slow. When he came out of the bathroom I helped him get dressed. By the time he was ready it was 9:30 and time to leave for Alois.

We walked to my car and got in. We drove to the Center. We exclaimed as always how beautiful the drive was. I turned onto Damon Road. A few seconds later we saw the facility on the right. The now infamous 'Alois Alzheimer Center' sign came into view.

He didn't appear to see it.

I pulled into the driveway under the portico. I stopped the car and got out. I closed my car door and got his walker out of the trunk. I brought it around to his side. I opened his door and he got out. He stood up straight and held on to the walker. We walked through the door together.

I vowed that he would leave there only if one of us was dead.

## Chapter 8: A Man Transformed (2005)

### Day One

Four hours. That was how long I'd visit Ed that day, his first full day at the Center. I woke up at 5:00 AM worrying about how he was doing. Sitting at my computer in my worn-out red sweats, doing double duty as pajamas, I checked my e-mail and drank my first cup of coffee. Even though it was Sunday I was working on a grant that had a quickly approaching deadline, but thoughts of Ed kept flashing into my mind and distracting me. I wondered how he could have possibly functioned without me in his strange new environment for even an hour the evening before, let alone all night and that morning. I felt as anxious as a mother whose little boy just spent his first night away from home at Boy Scout camp. At 8:00 I took a shower, then dried off and got dressed. I left for the Alois Center at 8:30.

I rushed into the lobby at 9:00 on the dot and hurried to the Assisted Living area, where they'd decided to initially place Ed. Consulting Ann's business card, on which I'd written the code, I entered 4231 on the keypad. Then I passed through the sun room with its little canaries. The area was infused with the inviting aroma of bacon. *Must have been served for breakfast.*

The aide, Alice, sat at a dining room table playing cards with two nicely-dressed ladies. One was wearing a cotton polyester print dress; the other, a dressy mint green sweat suit with white piping. The print dress lady, who looked a little befuddled, had her cards scattered on the table face up, while the other lady was holding her cards in her hands, guarding them from her opponent players. I wondered whether the respective care with which each lady held her cards was a telltale sign of the progression of her dementia.

Alice, the first and most cheerful of the aides assigned to Ed, was a young heavysset, medium-height woman with blue eyes and light brown

hair. That morning she was wearing a royal blue sweater flowing seamlessly over matching slacks.

I approached her, leaned over and whispered, "How'd Ed do last night?"

She looked up, holding her cards against her chest as though she thought I might sneak a peek and tell the others what cards she had.

"He did just fine."

"Great!" I said. I didn't believe her for an instant.

"He ate well, then watched a movie on TV with the other residents," she told me. "He did ask if I'd turn the TV to Fox News, but when I told him the others wanted to watch the movie, he didn't protest."

"Really?" I stated more than asked. "You're talking about *Ed*?"

"Yeah," she said. "He's in his room now. Go on down."

I hurried to the last room on the right, frowning as I was forced to skirt a slowly-moving lady arched over her walker. I was expecting to find Ed distressed and restlessly awaiting my arrival. Instead I found him sitting at a little desk the Center had provided, shaved and fully-clothed, his burgundy turtleneck making him look quite handsome. He hadn't worn it for years. Seeing him in it brought to mind 'the good old days.' The days way back when Ed had been so handsome and chivalrous. The days when we'd been inseparable. But those days were long gone. That day he was 92 and I was 55, and I was visiting him in a nursing home. He was calmly reading the newspaper as though he were at home, except at home he'd never be shaved or dressed at that hour. In recent years I'd been lucky if he'd shave and get dressed before 5:00 PM, if at all.

I entered and greeted him, anticipating an open-armed welcome, but he just looked up, smiled, and casually said, "Hi, Kitty." He acted as though I hadn't moved him to a place he'd sworn he'd die to avoid; as though he hadn't changed from living independently in a three-bedroom apartment to residing in one room of a long-term care facility; as though I hadn't gone off and left him overnight in that strange new place. I was surprised and, I must say, a little hurt.

He folded the newspaper carefully and placed it just so in the top desk drawer, which seemed odd. Then he walked over and sat down on the Early American sofa the Alois Center had provided until I could get his own furniture moved in the following week. I sat down beside him, crossed my legs and propped my feet up on the coffee table. We



discussed the horrible conditions in New Orleans, which he kept referring to as 'New York,' after Katrina had hit shortly before then.

Then he changed the subject. And not only that, he changed world geography.

"It's wonderful that we're 'leeving' here in Bucha-r-r-rest," he said. "Don't you think so? I've 'leeved' here all my life. It's in the whole world one of the most beautiful cities."

I could tell that one of the many hallmark symptoms of Alzheimer's was alive and well that day. Although he likely couldn't remember what he had for breakfast that morning, his memories of events from decades before seemed fairly intact. Of course he didn't live in Bucharest any more; hadn't for decades, but nonetheless I responded with the approach I'd been using for years, which was basically to agree with whatever he said in order to avoid a nasty argument.

"Uh huh. Bucharest is certainly beautiful."

Suddenly a stocky little man appeared in the doorway. His black trousers were hanging a couple of inches below his waist and his plaid burgundy and grey flannel shirt was untucked on the right side.

I was surprised when Ed, a lifelong loner, raised his hand and shouted, "Come 'een,' come 'een.'" Ed looked at me and said, "Kitty, this is my dear friend, John. We've been best friends for *years*."

John shuffled in, advancing in short jerky movements, his house-slipped feet barely lifting from the floor. Slightly balding, his remaining hair was jet black, his eyes dark brown, and he had a round jovial face that reminded me of my Irish Grampa Graves.

"Yes, we've been best friends forever," John said, waving at us.

Ed patted the empty space next to him on the other side of the sofa and John sat down. Then – and you might imagine my shock – they started holding hands and taking turns telling me how many years they'd been best friends. They reminded me of two little girls sitting on a bench, dangling their legs while waiting for the school bus. I was delighted – though dazed – that Ed had made a friend, and so quickly at that. Ed had never been one to make a lot of friends.

"Hi, John," I said, wanting to be gracious to Ed's new friend. "How long have you lived here at the Alois Center?"

He snapped to attention. "All my life," he answered proudly.

I shouldn't have been surprised, but for some reason I hadn't expected this man to be as confused as Ed.

The amount of time I spent visiting Ed would decrease little by little, but during those initial months I visited him every single day. On weekdays I'd go by after work for a couple of hours, and on Saturdays and Sundays I'd stay around four hours each time. So overall, we were spending about as much time together as we did before he moved. On weekends I'd arrive late in the morning. Sometimes we'd visit in his room, mostly discussing what he'd read in the newspaper or seen on TV, activities he soon wouldn't be able to do anymore. We also talked about mundane things such as what he ate for breakfast – which, not surprisingly, he usually couldn't remember – and occasionally what was happening in my life. Part of the time we sat in the Assisted Living unit's living room, where I observed the other residents out of the corner of my eye as we talked.

At noon I'd keep Ed company while he ate, then we'd go back to his room to talk some more before I'd leave an hour or so later. Ed always walked me to the door between Assisted Living and the lobby. He never seemed to realize he couldn't go any further because of the secured door. In the evenings we talked on the phone, another activity that would soon be too complicated for him.

One reason I visited so much was that I was used to taking care of Ed's every need, no matter how small. I helped him do so many things he could no longer do by himself. I helped him make phone calls, reminded him what phone calls he wanted to make, reminded him when his favorite talk shows were on and helped him find those shows on his TV. I felt compelled to continue performing those tasks because the aides at the Alois Center would have been overwhelmed by trying to give such detailed attention to each and every resident. They simply didn't have the time. I gradually stopped visiting every single weekday, but I still showed up a couple of evenings every week and many hours on the weekends.

In retrospect, I realize I visited so often simply because I needed to be needed.

### **Raging Anger**

"This woman is trying to r-r-run my life," he hollered, pointing at me with his shaky finger as I was telling the movers where to put his bookcases. "Get her out of here!"

I clenched my teeth. I was so angry I wanted to yell right back at him. That's exactly what I would have done had we been at his apartment. But I couldn't do it at Alois. They wouldn't understand that was the way we typically interacted. And regardless, I knew he didn't know what he was doing. But of course that didn't make it any less embarrassing and hurtful.

The movers were delivering his furniture and other belongings to the Center. They were the same four guys who had moved him into his Indian Creek apartment, and he was as irritable with me that day as he'd been then. He was yelling at the top of his lungs, which drew the attention of Kristi, who just happened to be nearby. She came to see what all the ruckus was about.

"Marie, I think you should leave," she told me.

"I was just going to leave anyway. I can't take this."

I was embarrassed and furious that Ed was causing me to be summarily removed from the premises in front of Alice, Kristi and the movers.

"It's not uncommon for residents to be upset when their belongings are being moved in," Kristi told me. "I'll consult with the Director of Nursing and she'll assess him and determine if there's a need for something to calm him," she said as we walked through the sun room, passing the tweeting, twittering canaries. "I assure you he'll calm down," she added, as though that was supposed to make me feel better about being yelled at.

*I don't give a damn if he calms down.*

I understood it was stressful for him and I felt for him. But it was stressful for me, too, and I didn't deserve to be treated that way, especially in front of other people. We walked through the lobby, where I told Kristi good-bye, walked out and got in my car. Then I slammed the door. Hard.

On my way home the sun was blinding as I drove across I-275. The sun visor wasn't helping so I put on my sunglasses. When that didn't help much either, I resorted to holding my right hand up to shade my eyes, keeping my left hand firmly on the steering wheel. I was relieved when I veered onto I-71 south and escaped the offensive orange ball in the eastern sky.

*Will Ed's raging anger toward me ever stop?*

**Vodka! Blessed Vodka!**

I got my answer the next evening, when Ed's next temper tantrum hit me as I was about to leave. It began as a pleasant visit, both of us admiring his room. It was cavernous – 13' by 25', and it was all his since I'd requested he not have a roommate. Beautiful teal and light blue patterned drapes covered the large windows, although the view wasn't spectacular. All you could see was the parking lot, but he seemed to have forgotten his grand view of the river at the Edgecliff, and didn't appear to mind at all. He never commented on it.

There was plenty of room for all his furniture. The bookcases were lining the walls with his nearly twelve hundred books. His furniture included the Early American sofa the Center kindly provided, which I'd decided he should keep because his wasn't all that comfortable. The room also held the black wooden coffee table he'd purchased at Contemporary Galleries, his well-worn imitation leather recliner and foot stool, his large Sony, a rocking chair and two chests of drawers (also provided by the facility), and his own little desk and desk chair. Even with all that the room wasn't the least bit crowded.

While Ed went into his bathroom I surveyed the room. It felt warm and cozy. The musty odor of the books evoked the essence of Ed in my mind. I ran my hand over the recliner and visualized Ed sitting there watching TV. The room had the feel of a place where Ed lived.

When it was time for dinner I left, walking Ed to the dining room on my way out. As we got closer, that evening's entrée – meatloaf – smelled so tantalizing I wished I could stay for dinner, but the staff had never invited me to stay and I'd never seen any family members eating there. So I resigned myself to what I'd planned for the evening: Stouffer's Lean Cuisine Lasagna – I think it had 280 calories or something.

"*Kitty*, would you please bring me two bottles of Popov tomorrow?" he asked sweetly as we circumvented two slowly-moving male residents.

One was carefully pushing his walker, neon green tennis balls attached to the back legs. The other was bent over, his silver cane glistening under the fluorescent lights.

"Kitty, I can't," I said, my body stiffening in anticipation of the ugly scene I knew would follow. "You're not allowed to have vodka here."

"What do you mean, I'm not allowed vodka to have?" he asked incredulously.

He stopped walking and glared at me.

"This is America! I'm allowed anything I want to have!"

"I'm sorry, Ed," I said, my voice wavering. "I can't bring you any. That's the rule here."

In a flash he became livid, yelling so loudly I was sure everyone in Assisted Living could hear.

"I don't need you!" he shouted. "I will find someone else to get it for me. And you can be sure. I will r-r-remember this!" he said, shaking his finger at me.

I winced at his outburst. I didn't want another major scene and I knew I couldn't win this battle, so, as much as it hurt, I turned my back on him and rushed out. I felt embarrassed as I passed Alice, who was setting the tables.

I slowed a moment and tried to save face by whispering, "He's just mad because I won't bring him any vodka."

"Uh oh!" she said, making light of it with a smile. I had the distinct feeling she was trying to lessen my embarrassment.

I left feeling tremendously hurt and went to my car, warmed by the unusual heat of the early September day. As I drove home, my Bach *Magnificat* CD serving as a backdrop to my thoughts, I felt sorry for Ed. I knew how much he *needed* his vodka and I wondered if he'd ever adjust to not having it. I began feeling guilty. I'd put him someplace where he couldn't even have a drink. He'd given up everything to come here, yet he was going to spend the rest of his life in a secured facility.

*What have I done?*

A few hours later Ed called and, as though nothing had happened between us, cheerfully asked me the address of "this place where I am 'leev-ing.'" Digging in my wallet to find Ann's card, I was pleased. I thought it was a good sign that he wanted to be oriented and know where he was. I told him the address and he repeated it one letter and number at a time, leading me to think he was writing it down, which I also thought was a good thing.

The minute I hung up I got it.

*Oh, shit! He's going to call Mr. Ellington to take him to Kroger's to buy vodka.*

I dialed Ellington's cell as fast as my fingers would move and explained the situation. Mr. Ellington promised to tell Ed his cab had broken down and it would take him a few days to get there. Mr. Ellington was a dear. I must admit, however, I was pleased Ed was still

alert enough to figure out how to try to get some vodka. I checked with Ellington later and found out that Ed had indeed called him.

A few days later I met briefly with Michelle, the Director of Nursing, about a urinalysis they'd done on Ed the day before. Michelle, a capable, decisive, no nonsense nurse, seemed imposing because she typically had a serious facial expression, but when you got to know her she was affable and had quite the sense of humor.

"By the way, Michelle, you'll never guess what Ed did the other night."

I began telling her about Ed's attempt to buy vodka.

"He *tricked me* into giving him this address and then he called a cab to take him to Kroger's so he could buy vodka! Fortunately, I had the cab driver's cell number so I called and told him not to come. I don't know what would have happened if I hadn't had his number."

"Oh, Marie," she said, leaning against her office doorway. "Don't ever worry about anything like that. We'd never let Ed go anywhere without calling you first." Then her eyes lit up. "You know, I've seen it all here. Residents have used various ploys to get out. We've even had the police show up, saying they were called by people reporting they were being held against their will!"

We both laughed.

Ed and his vodka had often posed a problem for me, one I'd tried to solve in various more or less successful ways over the years. Way back when Ed was 63 and I was only 26, and we'd been together for about a year, Freddie came down from Toledo for a long weekend. We were gabbing away and giggling as sisters often do while we drove through Eden Park on our way to Ed's place. The air conditioner was blasting on high, trying to overcome the fierce August heat that had been making everyone miserable for several days.

On the drive I mentioned to her my concerns about Ed's drinking. Even back then I thought he drank too much, although in retrospect, his consumption at the time was moderate by comparison.

"You know, Freddie," I said, turning slightly toward her, "I've started keeping track of the amount in the bottle. Sure enough, the levels are going down a lot faster than I think reasonable."

Freddie looked at me with an expression that conveyed disapproval, so I tried to justify my snooping.

"I've talked to him about it, Freddie, but every time he insists that he drinks 'little – *very* little'. Talk alone isn't going to help, and so I've been watering down his vodka."

She looked at me sternly and shouted, half serious and half joking, "Marie, that's horrible! You shouldn't trick him like that!"

She was right, of course, but that's what I was doing anyway.

Shortly after my confession we arrived at the Edgecliff. Freddie, wearing pink Capri pants, a matching pink tank top, white bejeweled flip-flops, dainty earrings and assorted other jewelry, and I, dressed in my usual uniform of worn jeans, a tee shirt, and old tennis shoes, went up to the ninth floor, where Ed welcomed us. Our dress was but a symbol of the enormous difference between us. Freddie was concerned about her appearance. I cared very little about mine. I loved intellectual banter; Freddie wanted to socialize and preferred small talk. But over the years we had figured out a way to remain close despite our differences.

Once Ed had let us in, I plopped down on the sofa, Freddie daintily sat down beside me, and Ed took a seat in his fake leather recliner. We began making light conversation and somehow the issue of vodka arose.

"I have to tell you an *unbelievable event* that happened the day before yesterday," Ed announced. "I got out of the fr-r-reezer my vodka to pour a drink and guess what? It was *f-r-r-rozen!*"

Freddie and I immediately figured out why. We stole a quick glance at each other and each saw the other was struggling to keep from bursting into laughter. After all, how would we explain to Ed why we were laughing so hard? We didn't dare look at each other.

Ed continued, his voice becoming more energetic, "I have kept in the fr-r-reezer my vodka *all my life* and it has *never* fr-r-rozen."

To hear him tell it, it was as though hell itself had frozen over.

"So I just put it in the 'oh-ven' to 'taw' it out!" he said with an air of finality.

This made us want to laugh even harder, but somehow we managed to hold it in.

A little while later we left to go back to my house. When we reached my car, we let loose and laughed so hard tears were streaming down our faces and we were literally doubled over. Every time we managed to stop laughing one of us would start again and then the other would, too.

For many years after, Freddie and I would laugh at the memory. Ed never did figure out why his Popov froze, but after that I put in less water, and as far as I know it never happened again.

Ed did soon forget all about vodka at the Alois Center. Never would I have believed that this stubborn, resolute, hard-drinking Romanian would never again ask for booze. It was so striking a change and it happened so quickly that I was alarmed. I watched helplessly as in a matter of mere months Ed deteriorated little by little physically and mentally. At each stage I became more dejected, knowing he'd never regain the skills he'd lost or return to his former state of health.

His temper got worse during his initial months at the Center as well. He yelled at me, he raised his voice at the staff, and he had outbursts with other residents, all over little things. This type of behavior is not uncommon in dementia patients, but common or not, it is usually embarrassing to their loved ones. I was no exception. His anger, although not at all new to me, was distressing.

At most facilities the staff members usually first try to redirect the resident's attention. But if that doesn't work and the outburst is strong enough and potentially dangerous to the resident or others, they may decide to give the resident a mild tranquilizer. I received several calls from the nurses at Alois to tell me he'd had yet another temper tantrum and they were going to give him an Ativan. Sometimes even the nurses seemed embarrassed, although I always told myself that they were used to this kind of behavior and knew that it was caused by the illness. Before too long, however, I would find a wonderful solution to this problem that would end most of his angry outbursts. But not before the situation got even worse.

### **The Unthinkable Happens**

I was lounging around in my black wolf sweatshirt, the one Ed had always forbidden me to wear in his presence, when the phone rang. The night nurse, Joyce, had shocking news for me. The unthinkable had happened.

"Awhile ago Ed slapped Marty, the dietician, and then pulled her hair," Joyce said. "Another employee stepped in and he let go. Marty wasn't hurt," she added, "so don't worry about that."

Joyce sounded rather calm considering the nature of what she was telling me.



In the thirty years I'd known Ed, he'd never been violent. He could lose his temper, gesture wildly and yell a lot, but he'd never so much as raised a finger to anyone. If he had I would have ended the relationship on the spot. Given my experience as an abused child, I'd never stay involved with *anyone* who was violent in any way. But there I was, faced with the fact that the man I'd loved for so many years had actually struck someone. Not surprisingly, my initial reaction was anger.

"You can't be serious," I said, getting up from the sofa and starting to pace the floor. "I can't believe this. I'm so sorry! What happened?"

"He was in the dining room with several other residents after dinner, reading his newspaper," she said. "We were having a guest speaker for a public presentation, so the staff had to move all the tables and position the chairs for the audience. All this commotion caused many residents – not just Ed – to become agitated."

"I don't really care how many other residents were agitated," I told her angrily. "I'm really upset and worried that he was violent and actually struck someone."

"Don't be upset, Marie," she said. "We consider Ed's behavior a one-time incident, and don't feel it's necessary to follow up. Physical violence isn't characteristic of Ed. It is with some of our residents, but not him. And to be perfectly honest, we've found in the past that overstimulation can cause aggressive incidents. In a way, really, it was our fault. We should have taken the residents back to their rooms before we started rearranging the chairs."

"I'm still upset," I said. "What will happen now?"

"Nothing, really. We are simply required to inform you of the incident. Ed is calm now."

"What a relief. I was worried you'd tell me you might have to discharge him."

Joyce assured me that there was no real cause for concern. When I got off the phone I just sat there letting what Joyce had told me sink in. Peter must have sensed something was wrong. He sat down on my lap and began wagging his tail and licking my face. While petting him I closed my eyes and sighed.

*How could he?*

Right then I was so upset I didn't want to even visit Ed. His behavior triggered memories of my past and all the violence that had been part of it. I felt overwhelmed by those memories and appalled that Ed had

actually hit someone. It felt as though he'd struck *me*. I felt about Ed the way I'd felt about my father when *he* hit me. I just couldn't go to see him, because visiting him and being all sweet and loving would feel like condoning, or at least overlooking, his behavior. I knew that was a ridiculous way to look at it because unlike my father, Ed was demented and couldn't really be held responsible. But feelings aren't rational, and I just couldn't help being angry. Ann, the Center's social worker, had warned me. "Just when you come to terms with their state of illness," she had said on several occasions, "they get worse." Well – he'd just gotten worse. And although the Alois Center didn't seem particularly concerned, his behavior disturbed me deeply and it took several days before I could come to terms with the situation and go visit again.

### **Downward Bound**

"You're moving him to the Courtyard?" I asked Ann as I increased my cell phone's volume. *I really do need to get those hearing aids.* "He's only been there for a month."

"We give every resident a chance in Assisted Living first if it seems at all feasible," she said. "We thought Ed might be able to function there. But he needs more personal care than Alice and the other aides can provide, and he's also requiring more nursing care now, too. A room has just opened up in the Courtyard and we'd like to move him there tomorrow."

"Tomorrow?" I asked, leaning forward in my recliner and raising my eyebrows.

I couldn't believe it. I'd been so pleased they'd started him out in Assisted Living, the unit for their healthiest residents. It had given me comfort that they'd considered him in good enough physical and mental shape to live in their relatively low-care unit. I'd even been proud of him in a way. I couldn't believe he'd declined so quickly that he needed to be moved 'downward' already. And a 'downward' move it was, in my eyes; his third in four months. He'd moved from the Edgecliff to Indian Creek and from there to the Alois Center. But even worse than my reaction to his steady decline was the fact that he and Alice had developed a close bond during the month he'd been there. Now he'd have to adjust to new aides, and I worried they wouldn't be as devoted as Alice.

On the day they moved him, June, the main Courtyard aide, a large young woman with long blond hair cascading down her shoulders, came to Assisted Living to occupy Ed in the dining room. They talked, ate chocolate pudding, and had decaf while the Alois maintenance men moved his belongings, including the eight bookcases and all their books, into his new room at the end of the Courtyard corridor. Ed was oblivious to all that. He talked about his books, ate his pudding, told June how beautiful she was, how lucky he was to have her presence, and how much he liked the pudding. When everything had been moved, Alice walked Ed to his new room and told him matter-of-factly, "This is your new room, Edward." Then she said good-bye, turned around and left him with June.

As all this transpired, I was sitting on the mahogany and gold striped sofa in the living room of the Assisted Living unit. When Alice returned, her blue eyes were downcast, her lower lip quivering. She burst into tears the instant she sat down.

"I'm going to miss him so much," she said, sobbing, her mouth gaping open, tears falling down her cheeks. "He's such a dear."

I didn't know how to make her feel better. I got a Kleenex packet from my purse and held it out to her. She took one then dried her eyes and blew her nose.

"At least I didn't cry when I was with him. I did that once when I was taking a resident to his new room and I got in trouble for upsetting the resident," she said.

After a few moments she regained her composure.

"I'll go over and visit him later today," she said.

I had the feeling she might be going over regularly for some time. Seeing that depth of affection – you can't fake bursting into tears – from an aide who'd cared for Ed for only one month, I was sure I'd selected the right facility.

### **Forlorn and Lost**

I decided it was time to see how Ed was adjusting. On my way to his new room I peeked into the activities room and saw an angry-looking woman cradling a teddy bear wrapped in a little white blanket. I later learned the woman's name was Carol. She was overweight and had a big stomach and a reddish puffy face. Her gray hair was so thin she almost looked bald. She was wearing an off-white sweater over a white

and blue polka-dotted blouse. They told me she'd been a reference librarian at a large southern university for twenty-five years.

"Can you unlock the door for me?" she asked. "My children are coming to take me to Arizona."

"I'm sorry. I don't know how to open the door," I lied.

With that I turned and continued down the hall. I passed another resident, this one standing still in the middle of the hallway and facing me, looking straight ahead with a vacant facial expression. She was wearing pink sweats I suspected might actually be a jumpsuit. It was kind of hard to tell. The top portion had little crimson roses arranged in the shape of a heart. She was tall and thin – almost as thin as Ed – and was wearing glasses with remarkably thick lenses. Apparently she didn't only look lost, but actually was. Just as I passed her, an aide gently took her arm and said, "Joyce, come dear. I'll help you find your room. It's at the other end of the hall."

When I reached Ed's room, I expected to find him disoriented, agitated and upset. But he was calmly sitting at his desk. Wearing his khaki Dockers and a crisp red and white pinstriped shirt, he was reading, or at least trying to read, what looked like a philosophy book, probably in German. Most of his philosophy books were in German. June, wearing vibrant violet scrubs, came in and introduced herself.

"Are you his daughter?" she asked.

That age-old embarrassing question again. I wished she hadn't asked. It got so tiresome.

"No. We've been best friends for nearly thirty years."

"Oh. I see."

No. I was sure she didn't see. No one did unless I recited the whole long story.

"Looks like he's right at home," I said.

"Yeah. Residents usually get used to their new rooms pretty fast," she said, "especially when they don't see their stuff being moved. And when we put everything the same exact way it was in their old room, they don't even know they've been moved!"

She laughed at her own remark.

"It usually takes the families longer than the residents to adjust. He'll be fine. Don't worry."

June didn't seem to have quite the warmth Alice had, but I knew I'd have to wait and see.

As I left the Center a little while later, Ed accompanied me to the front door. In Assisted Living he'd only been able to go as far as an internal door, but from his room in the Courtyard he could go with me to the main door of the facility.

As we were walking, an elderly man I'd noticed during one of my tours at the Center slowly passed us in the hallway. Maria, the friendliest and most cheerful receptionist, told me he was Mr. Brooker, who used to be a stock broker, and that he came every day at noon to stay with his wife, Denise, in the Terrace. Maria added that Denise was usually asleep, but he stayed for a long time, usually three hours, anyway. She said he was really broken up over his wife's condition and the staff members felt sorry for him. When Ed and I reached the front door we went through our ritualized leave-taking, saying good-bye and blowing kisses to each other.

"When are you coming back?" he asked.

"Tomorrow," I answered.

He asked me that every time. And I always said "tomorrow." I wanted to please him and he wouldn't know the difference anyway. But instead of responding with his usual "Marvelous! Superb!" he looked bewildered.

"What should I do now?" he asked plaintively.

"Do whatever you want," I answered as I waited for the door's thirty-second delay to pass.

"I don't know what to want," he said.

I was blindsided by his remark. He seemed so lost.

"Well, why don't you just sit in this nice chair here for awhile?"

He sat down obediently.

"How long should I sit here, Kitty?"

"Sit however long you want," I said, turning from the door and walking back toward him.

"Kitty, I don't *know* how long," he said, looking forlorn.

"Okay," I said. "You sit here thirty minutes."

"Thank you, Kitty. I will sit for thirty minutes here. What should I do then?"

He looked at me as though I had the answer to all of life's questions, including that one. My heart sank as I realized he had reached the point of needing specific instructions for what to do every moment.

“Sit here in this chair for thirty minutes,” I said, kneeling in front of him. “Then go to your room. When you get there, get ready for bed. I will visit you again tomorrow.”

*As though he could remember all these instructions.*

“Oh, Kitty,” he said, “Thank you for your guidance. It r-r-really means so much to me.”

And with that we blew each other kisses again and I left. I was completely overwhelmed by his further descent into dementia. This formerly brilliant lawyer and professor could no longer even decide how long to sit on a chair.

### **Struggling to Cope**

“Kitty, I’m so happy to hear your voice, little Kitty,” Ed said loudly over the phone.

He seemed perfectly lucid, but he was speaking in a loud, high-pitched voice. He sounded terribly upset.

“I have to tell you something horrible, Kitty. I was *beaten* this morning.”

I gasped.

*How could this be?*

“My body hurts all over,” he continued, his voice cracking. “They knocked me on the floor and beat me with their fists and kicked me with their feet. I wish you had been here to make them stop. They wouldn’t stop.”

He sounded so coherent and convincing that in a moment of sheer terror I found myself wondering if maybe someone *had* hit him. TV news stories of abuse in nursing homes flashed before my eyes and I felt nauseous. I knew mistreatment did occur in such facilities, but it couldn’t possibly happen at the Alois Center.

*Could it?*

I closed my eyes and a vivid picture of Ed, so frail and helpless, being punched in the face came into my mind’s eye. I winced as though someone had just hit *me* full force. I jumped up from the sofa and started pacing the floor.

“Six aides beat me for half an hour without stopping a moment,” he cried out. “And it was led by my good friend – my aide, June. I called out for help but no one paid any attention. No one came to help. They just kept hitting me.”

I struggled to breathe. It was conceivable that one bad apple could have found its way onto the Alois Center's superb staff, but not six. While one aide could hit a resident in a closed-door room, six could never hide their actions. So I was convinced that the whole story was a delusion. Nonetheless, I was still shaking and felt dizzy. I sat down on the sofa again and collapsed into the cushions. He seemed so lucid – more so than he'd been for months – and he made this whole sordid story sound so real. It stalled me for awhile until I finally figured out an appropriate response.

"Ed, I think you're a little confused," I said, trying to calm both him and myself. "I think you must have had a bad dream. I don't think anyone there beat you."

"I can understand why you're skeptical," he said, still sounding perfectly cogent. "I understand why you think it was a dream because it's such a horrible thing no one would believe it."

He lowered his voice.

"But I can assure you Kitty, it wasn't a dream. It's true. I have the bruises to prove it. And witnesses I have," he said, his voice trembling. Then he resumed in a louder tone of voice, "I called my lawyer, Stuart Susskind, and there's going to be a trial. It will be proven that they beat me. They will all go to jail for a long time."

His tone of voice and all the details he provided made me waver. He even remembered his lawyer's name. I was devastated because it was obvious Ed was suffering emotionally just as much as if he *had* been beaten. Worse still, there was nothing I could do to make his nightmare go away. Ed was in distress and I couldn't help him at all. Memories of that conversation haunted me for days, although when I went to visit Ed the next day, *he* had forgotten all about it.

At that point Ed had been at the Alois Center for four months. He continued to have delusions. He also performed obsessive-compulsive rituals and suffered from sleep disruptions, depression and often had angry outbursts. I could see he was struggling to cope.

One of his obsessive compulsive rituals involved the newspaper. After breakfast he'd carefully tear his newspaper's front page away from the back page. Then he'd tear the front page into four neat quarter pages. Next he'd take one of those and tear it into four equally-sized strips. Then he'd spit on each and use it to wipe the dining room table, smearing newsprint all over. The aides told me he repeated that precise

routine every morning. His behavior didn't really hurt anything or anyone, and so they just let him be and cleaned up the table afterward.

Ed also took the dining room paper napkins to his room, where he folded them neatly and placed them on his coffee table, right on top of his bright multicolored runner. He always put down the same exact number – eleven – five on the top row; six on the bottom. He got upset if anyone touched them or, God forbid, moved them.

His sleep patterns were problematic, too. The aides told me he often stayed awake all night, moving from one seat to another in the lobby as though playing musical chairs. Sometimes he'd wander the hallways, which was even more problematic, as he might disturb other residents. So when they had time, the aides would sit down and talk with him over decaf in the dining room. Yet his nighttime activities interrupted his sleep cycle and daytime routines, which is typical of many Alzheimer's patients. He was tired and would often sleep during the day and miss his meals. The staff didn't usually awaken sleeping residents for meals.

As for his mood, at times he was cheerful and a joy to be with, but other times he was despondent, his head drooping, eyes downcast. His mood was contagious, and after some visits I felt depressed myself, went home and spent hours lying on the sofa. With Peter draped across me, I'd find myself staring at the TV without noticing or caring what was on.

Worst of all, though, were his repeated angry outbursts toward me, the staff and other residents. When he lost his temper with me, sometimes I didn't want to visit for awhile. And sometimes I actually didn't. Alzheimer's patients' behaviors often lead to tension between the patient and the primary caregiver, and it's normal for caregivers to feel anger and resentment at times. I knew he couldn't help it and I felt guilty for being mad and visiting less, but I was only human and I could only take so much of his temper. *Knowing* he couldn't help it was one thing; standing there and allowing myself to be yelled at was another.

### **Bicycle Camping**

I had serious trouble adjusting to life with Ed at this new stage, and I finally decided I needed a break. I hadn't had a vacation in years because I couldn't have gone anywhere and left Ed alone. When he was still living by himself he needed me just to get by on a daily basis. But since he was at the Alois Center, it dawned on me that I could go



anywhere I wanted and stay as long as I cared to. I decided to go visit Marsha in San Francisco.

On the flight out I found myself chuckling at the memory of our famous bicycle camping trip back in the late '80s. I'd bought a bicycle, determined to start getting some exercise and lose some weight. Marsha immediately decided she wanted one, too. When we went to show Ed our bikes that day he told us the saddest story. He said that when he was a child his grandfather took him out one day and bought him a beautiful red bicycle. But when they got home, Ed's father said it wasn't safe for Edy (as it's spelled in Romanian) to be riding a bike on the streets of Bucharest, so he made them return the bike. Ed never did learn how to ride a bicycle.

The highlight of our biking days was a weekend camping trip to East Fork Lake State Park, about thirty miles from my house. First we mapped out a route on back country roads to avoid traffic. Next we hit the camping store and bought all manner of lightweight gear – tiny one-man tents, thin three-quarter length air mattresses, a miniature camp stove – you name it. Then we loaded all this stuff, plus clothes and food, on our bikes and headed out for the lake.

After we arrived nearly three hours later and unpacked our gear, an odd-looking middle-aged couple in a nearby old RV came over. The woman was a good eight inches taller than the man and looked about twenty years younger than he. They were both wearing shorts, white tee shirts and sandals with white socks.

"Hi, how you gals doin'?" the woman asked. "I'm Nancy and this is my boyfriend, Willy."

We said hello and introduced ourselves. Seeing their appearance and hearing their accent made me curious to learn more about them.

"Where's your *car*?" Willy asked, pointing to the empty paved spot where a car would normally be parked.

"We don't have one," Marsha said, laughing. "We rode our *bicycles* here from Cincinnati!"

"How'd you get all yer stuff here?" Willy asked, his eyes darting around our campsite.

"We brought it on our bikes," I said proudly.

"No. *Really*," Nancy said. "How'd you get these here tents and everything here?"

"Honest," I said. "We brought everything on our bikes."

We were bursting with pride that Nancy and Willy were so incredulous about our feat.

"Gee, what brave gals!" Nancy said. "What would you have did if one of yer bikes broke down or somethin' on one of these ole country roads?" she asked.

"Oh, we have all the tools we'd need to make repairs," Marsha said, sounding confident.

I knew she wasn't really confident. Neither was I.

"Yer still brave. I shore wouldn't try anything like that. In fact I couldn't even ride a bike half that fur with *nothin'* packed on it," Willy said. "Hey, listen! We're gonna grill out tonight. You gals come over and git you some burgers."

"Oh, thanks. We will!" I said.

We did, and the burgers were some of the best we'd ever had.

It wasn't really very smart for two middle-aged women with no experience making emergency bike repairs to go on a trip like that. It was way before cell phones, and so we couldn't have called for help if we'd had a mechanical problem or one of us had gotten sick or injured on those back roads. But dangerous or not, it was *absolutely* the most enjoyable thing we ever did together.

Marsha moved to San Francisco the following year to accept a position at the University of California, Berkeley. I was devastated to lose her companionship, but there was an unspoken bond between us. Marsha was the kind of friend who would drop everything and fly half way across the country to come take care of you if you needed her. And not only *would* she do it, she actually *did* do it a few years after Ed's death when I got breast cancer. I'd do the same for her, but hope the circumstances to let me prove it will never arise.

### **Another Friend's Advice**

My first full day in San Francisco Marsha and I went on a tour of Napa Valley, during which I brought her up to date on Ed's condition. The next day we decided to go to San Francisco for some sightseeing. We were planning to see the Golden Gate Bridge, visit Ghirardelli Square and Pier 39, and take a cable car ride. It was Sunday and Marsha's husband, Jim, was playing a concert with the Golden Gate Park Band, so we went by ourselves.

As we were approaching Ghirardelli Square, we came upon a tiny coffee shop with two street musicians in front of it – a drummer and a trumpeter both dressed in silver sequined shirts and pants – playing Dixieland. We decided to drop in. The irresistible aroma of coffee blended with the sonorous tones of light jazz emanating from the overhead speakers greeted us. The place was packed. We decided one of us would stand in line while the other found and saved a table. She volunteered to do the line duty. Just then two bearded young men got up from a pair of side-by-side massive forest green corduroy-covered arm chairs that were angled toward each other and had a large round table in front of them. I sat down in one of the chairs and dropped my purse on the other.

Marsha and Ed had always argued bitterly about politics. They had such incredibly different points of view they could hardly have a civil discussion about anything except who the President *was*. I especially remembered the fight they had the day Carter pardoned the Viet Nam War draft evaders.

We'd met at Ed's apartment before going out to dinner. As usual, we sat in his living room, he in his recliner and we on the sleek sofa, and had a glass of Robert Mondavi wine. That's when Ed raised the issue. He'd just finished watching Walter Cronkite and was considerably.

"You'll never guess what did that idiot, Carter," he said angrily, putting down the remote control, or the 'commander' as he called it, on the little side table beside his recliner. "He has pardoned all the damned draft dodgers after so many courageous young Americans fought and died for this country. And on his *second* day in office he did it. It's an insult to all those soldiers who died and their families." Then he raised his voice even more. "That despicable man has no sense of *justice*."

Having made his point, he put his feet up on the ottoman and crossed his arms, a defiant expression on his face.

"Well I *agree* he has no sense of justice," Marsha said firmly. "If he had any sense of *justice* he would have made the pardon *broad*er."

She was annoyed at both his opinion and attitude, and was eager to argue with him.

"Oh, you're wrong! *Excuse* me, Marsha!" he yelled, shaking his finger at her. "He pardoned draft dodgers and army deserters. Who else *could* he have pardoned?"

"Well, Ed. That just shows your *ignorance* of how limited the pardon really is," Marsha yelled back, staring at him intently. "The pardon does *not* cover deserters," she said condescendingly. "It only covers those who left the country and those who didn't register for the -

"Yes, it *does* cover deserters! I'm sorry!" he interrupted, shaking his finger at her again. "Don't you ever listen to the *news*?"

"Yes, I *do*. And I read the *papers*," Marsha shouted, leaning forward and opening her eyes wide, staring at him intently. "And *you* don't know what you're *talking* about. The pardon does *not* cover deserters."

I personally had no earthly idea what the pardon covered and honestly didn't care. I was, however, curious enough to look it up later, and discovered Marsha was right. At the time I was very uncomfortable with the whole situation. I didn't keep up with the news enough to join in and even if I had known what they were arguing about I would have kept my mouth shut. They always lost their tempers, called each other names and made scenes I didn't want any part of. I preferred to just sit on the sofa and wait for them to finish.

This particular argument raged on and on then it turned to the *more* controversial issue of why we were in Viet Nam in the first place. At one point Ed delivered an especially long and acrimonious tirade that ended with him hollering at Marsha that she was a 'bleeding heart liberal.'

Just as she was preparing to strike back he suddenly looked at his watch.

"Oh!" he said pleasantly. "It is nearly 7:00. If we want dinner to have we should probably now 'leev,' don't you think, Marsha? And you, little Kitty?"

I was surprised he acknowledged I was in the room.

"Yes," Marsha said in an equally pleasant tone of voice, looking at her own watch. "You're right, Ed. I'm starving."

"I'm starving, too," I said blandly. It was the only thing I said the whole time.

"Where you want to go, Ed?" Marsha asked.

And that was it. The argument was over. The three of us got up, put on our coats, and decided to go for a steak dinner at Victoria Station, a popular restaurant located inside several adjoined railway cars. We had a lovely evening and nothing more was said about Carter, the war or the pardons.

Ed's politics never changed, though. Later in his life, when his dementia was already taking its toll, Ed still insisted on voting. He'd voted in every election since he came to the U. S., and he sure would that year as well. I was amazed he still knew *exactly* where his polling place was, but he needed my help to actually cast his vote. So we both went into the booth and closed the curtain behind us. He couldn't see the names clearly so I started reading them to him. Given his hearing problems I had to do so in a rather loud voice. He knew the candidates in the first three races and told me which ones to vote for. But then he became confused, and finally he just shouted – very loudly – “Just mark all the Republicans!”

To this day I have to smile every time I think about that, although that day in San Francisco with Marsha I was sad, longing for the days when he was lucid enough to fight over intricate political details.

“Marsha,” I said as she returned with our drinks, “I just wish there was something I could do for Ed. *He's* miserable with his depression, delusions and sleep disruptions and *I'm* miserable with his temper tantrums.”

I cautiously took the lid off my cappuccino.

“You know, Marie, I've been thinking about everything we discussed yesterday. I know Ed has dementia and there's nothing you can do about *that*, but I remember one of my golfing friends, Joyce, an internist, mentioning to another friend that some Alzheimer's patients can actually be helped by psychotropic medications.”

Marsha took a sip of her drink then put it back down on the table.

“Joyce said the drugs don't make the patients any less demented but can help with symptoms such as depression or delusions. They might help with other symptoms, too. I don't know.”

“Huh. I never thought about that,” I said.

My attention was momentarily diverted as a baby at the table next to us started crying, and I couldn't help but remember how much Ed hated being seated next to children or babies.

*If Ed were here we'd have to get up and move all the way to the other side of the room.*

“You know, some of his symptoms could actually be resulting from depression,” Marsha continued. “If you could get rid of his depression, perhaps some of his behavior problems would disappear, too.”

"*That* would be wonderful," I said. "So he'd still be demented, but might be less depressed, angry and delusional? And might start sleeping better?"

"That's what Joyce said. And apparently there are also medications for obsessive-compulsive disorder. It might be worth seeing what a doctor thinks," Marsha said.

We'd both finished our coffee by then.

"Want another drink?" she asked.

"Sure. And let's get a dessert, too," I answered, my mouth watering at the very idea.

While we'd been talking the place had cleared out so we just went up to the counter together, leaving our coats on the chairs. There were so many tantalizing desserts it was difficult to choose. In the end I picked iced lemon pound cake – I *loved* lemon pound cake – and Marsha decided to complement her fat-free latte with a large slice of strawberry cheesecake.

"You never think about getting a psychiatrist for an Alzheimer's patient," I said. "But what you said makes sense. Come to think of it, Ed might have benefitted from such medications even before Alzheimer's got the better of him."

"I suppose," Marsha said. "Maybe his heavy drinking was also an attempt to self medicate undiagnosed depression."

"I *never* could have made him see a psychiatrist," I said emphatically.

"Well, I agree with you on that!" Marsha laughed, digging into her cheesecake. It looked so good I almost wished I'd gotten that instead of the pound cake. Back in the days before my dramatic sixty-five pound weight loss I'd have thought nothing of having both.

"I wonder how he'd react to it now?" I asked.

"I don't think you even have to tell him the doctor is a psychiatrist," she said. "You can just have the doctor go see him. Then if he prescribes any medication, the nurses will just give it to him along with his other pills. He'll never know the difference."

"True. He's so demented he probably wouldn't understand it even if I did tell him."

"Exactly," she said.

"You know what, Marsha? I'm going to take your advice. There's really nothing to lose and everything to gain."

I thoroughly enjoyed the rest of my visit, but was anxious to get home and try out Marsha's idea.

### **Remarkable Changes**

"I'm going to call in a geropsychiatrist," I told Teresa, who'd come to visit Ed with me the day after I got back from San Francisco. "Many of Ed's symptoms are due to dementia, of course, but I still want to have a psychiatrist determine whether psychotropic medications might help with some of his *other* symptoms."

We were talking in the lobby, amidst many residents, some alone, some in pairs; a few sitting, others walking around. Jane, dressed in a tan cable-stitched sweater and azure blue wool slacks, was taking her habitual laps around the room's perimeter. I'd been told that walking was her main joy in life. She had a special relationship with Peter. I often brought him to Alois because Ed and the other residents really loved seeing him.

Until two months before this, Jane had never even answered my greetings, let alone talked to me. In fact, I'd never heard her say anything to anybody. The first time she saw Peter her face lit up and she stopped to pet him. He got excited, of course, and jumped up on her legs. With her leaning down, him jumping up – his tail moving so fast it was a blur – their faces met and he licked her gleefully, bringing an even bigger smile to her face. That same scene was repeated during many visits. Then one day when I went without Peter, Jane actually looked at me and asked in the softest voice imaginable, "Where's the *dog*?" After that every time I went, with or without Peter, Jane said a few words to me. So Peter was actually a therapy dog.

"It sounds like a wise idea," Teresa said, shaking me from my reverie. We walked to my car and drove to the Cheesecake Factory in Kenwood, our choice for lunch that day. I filled her in on my talk with Marsha about getting a geropsychiatrist.

"You know, many families are aghast at the very idea of putting their demented loved ones on psychiatric medications," I said. "They fear they'll be 'drugged into submission.' That's how those drugs were typically used in the past. Nursing home doctors used to administer such high doses of the older drugs that patients often turned into zombies. But Marsha tells me that newer medicines can reduce troublesome behaviors

and improve patients' overall mood and functioning *without* sedating them all that much."

"Just be prepared to be patient," she said. "I have a friend who is taking an antidepressant and she said it took almost four weeks before she noticed any improvement."

"I'll wait," I said. "Anything is better than the present situation, no matter how long it takes."

It was with great anticipation that I arranged an appointment with a highly respected Cincinnati geropsychiatrist who also treated several other residents at the Alois Center. He diagnosed Ed with depression and obsessive-compulsive disorder. He initially prescribed Desyrel for Ed's depression and Luvox for his obsessive-compulsive disorder. Soon he added Zyprexa to help stop Ed's periodic psychotic episodes. He also prescribed Aricept for his dementia.

I have to admit I was concerned about the Zyprexa. Based on my own research I'd learned that Zyprexa wasn't really recommended for elderly dementia patients because it was associated with an increased risk of stroke and death in that population. I had to give that serious thought. Were the *possible* side effects prohibitive, or should I opt for a chance at a better quality of life? Ed was 92 years old. How much longer could he possibly live anyway? It was an agonizing decision, but in the end I decided to go for a chance at a better quality of life rather than a potentially longer life disturbed by the type of frightening delusions and hallucinations he'd been having.

I sat back and waited to see what would happen. I carefully observed Ed's every behavior and daily mood, waiting to see whether those medications would help. I waited. And waited. And waited some more. Finally, after about three weeks it paid off. Ed still had delusions but they were much less frequent and less intense. Most surprisingly, his obsessive-compulsive behaviors *completely* stopped. No more torn newspaper strips, no more folded napkins, no more rituals of any kind. Furthermore, he began sleeping more at night and napping less during the day. His angry outbursts decreased dramatically, although he'd still have an occasional fit.

His appetite improved as well. He'd been seriously underweight all his life. He was 5'8" and had weighed only 102 pounds when he entered the Alois Center. But during one of my visits some time after he'd started the medications a nurse came in and asked me to buy him some larger



pants. He was up to 113. And a few months later the request was repeated. He was up to 124. I was delighted. The most I'd ever known him to weigh was 125, and that was when he'd *temporarily* gained weight when he quit smoking.

The most dramatic change, however, was his overall mood. In a word, Ed was transformed, and fantastically so. Yes, he was still demented, but most of the time he was the most contented, loving and loveable person you'd ever want to meet. Definitely *not* your typical Alzheimer's patient. He said repeatedly how lucky he was to be at the Alois Center and how joyful he was to have all the people there who took care of him. He thanked every person every time they did anything for him, no matter how small.

Mary, the housekeeper, went in one day and emptied his waste paper basket.

"Oh!" he said. "Thank you! Thank you so much!"

Then he kissed her hand.

"You are *so beautiful* and I am so lucky to have your help."

"You're welcome, Edward," Mary said.

"I really *mean* it," he added. "It's from my heart – not just words from my lips. I am so lucky. When are you coming back?"

"Soon," she said,

"Wonderful! Thank you! I'll be here."

You can imagine what he said to his aides when they showered, shaved and dressed him.

And he was absolutely wonderful with visitors. One day I arrived and found our mutual friends, Dinny Jergens and Dick Shepherd, just finishing up a visit with Ed. I'd been friends with Dinny, ten years my senior, almost as long as I'd known Ed. She was originally married to Andrew Jergens of the Jergens soap company. When they divorced she ended up a millionaire. Then she'd married Dick, a former Proctor and Gamble executive. Ed was sitting on the sofa beside Dinny, whose short silver hair shone under the room's bright incandescent lights. Ed was holding her hand. The aides told me he often held his visitors' hands – even those of his male visitors – the whole time they were there.

"We need to leave now, Ed," Dick said after a few minutes.

Dick was nearly Ed's age and looked it, but he was still in full possession of his faculties. He stood and reached for his navy parka, which he'd draped over the rocking chair.

"We're going to meet Dinny's son, Peter, for lunch," he told Ed.

"Oh! Certainly!" Ed said, smiling and still holding Dinny's hand. "Thank you so much for visiting me. I am *so lucky* you came to see me." You are both *so* beautiful!"

He kissed Dinny's hand several times in quick succession and said, while looking up into her eyes, "Thank you for coming."

Then he looked over at Dick and asked his standard question. "When are you coming back?"

"Tomorrow!" Dick answered enthusiastically.

I had coached him to say that.

"Marvelous! Superb!" Ed said.

A week later, I was signing out one afternoon when Maria, the receptionist on duty that day, turned from her computer screen and said in her lovely Italian accent and with a twinkle in her dark brown eyes, "I bet that Edward was a real lady's man in his day! Every time he comes up here he tells me I'm the most beautiful woman in the world, and that it's not just words from his lips – that he really means it from his heart."

I laughed. I was tempted to tell her that Ed *had been* a lady's man and that *I* had been one of his ladies, but I chose not to.

"Yes," I said, "he was quite the lady's man," and I left it at that.

Later on, one Saturday morning as I was getting my usual candy bar and Diet Coke from the vending machines, I turned and saw Susan Gilster, the Alois Center Director, dressed stylishly, as always, walking briskly through the dining room. She paused a moment, smiled, and remarked, "No wonder you're so close. He's *adorable!*"

Her comment made me smile and feel warm inside.

The most charming comment I heard about my newly-transformed Ed, however, came from Debbie, an extroverted young girl who worked in the kitchen. I was sitting with Ed as he was finishing his lunch one day when she came out and started talking with us. She was quite a sight – black slacks way too long, all bunched up at the bottoms; a worn-out orange tee shirt with a hole in one sleeve; a white apron, the obvious recipient of a bit of that day's lunch; all topped off by a neat state-mandated hairnet. She stood by the table, put her hands on her ample hips, cocked her head and asked Ed in her usual loud tone of voice, "Where were you when *I* was looking for a husband?" I burst out laughing. Ed laughed, too, then reached out for her plump hand and

planted several big kisses on it. He finished by telling her how beautiful she was.

Clearly Ed was far more at peace than before. Right or wrong, I attributed those remarkable changes to the medications that doctor had prescribed. I never met the man, but in my mind he significantly changed Ed's life and our relationship. To me he was the most important health care professional ever involved in Ed's care either before or after he entered the Alois Center. I always wondered how many of the other residents had similarly benefitted from his care, and I always hoped that other families would consider consulting a geropsychiatrist for their loved ones with dementia.

Yes, Ed had been transformed, and I was both relieved and delighted that he was feeling so much better. But despite all the improvements in his mood and behavior, he was still *demented*. I'd known this would be the case, but I still missed the Ed I'd known before dementia hit. Badly. I didn't think I'd ever adjust to the new person Ed had become. He was so demented I couldn't have a meaningful two-way exchange with him. He couldn't talk with me about my problems and successes. He couldn't provide emotional support and be there for me no matter what. I was saddened by my tremendous personal loss and often felt overcome with emotion when I remembered the years gone by.

The new Ed was contented and loving, but I was still suffering. I knew that as time went by it would only get worse. I'd helped him adjust as much as I could. But I didn't quite know how to help myself adjust and live with the loss of that great man I had loved so much for so long.

## Chapter 9: Caregiver Distress (2006)

### **Tears for *Yesterday***

I am a person who almost never cries. Maybe once a year. If at all.

I wandered into the Center, dressed more nicely than usual that day – a powder blue silk blouse over grey wool slacks instead of my usual jeans and tee shirt. I'd dressed up that morning because I had to attend Ed's quarterly care conference and wanted to look nice. These quarterly meetings were held with the Director of Nursing and other key staff to review each resident's mental and physical condition with the family. In Ed's case, I was 'the family.'

After the conference I went to Wendy's for lunch and had my usual single with lettuce and tomato and my favorite dessert, a chocolate Frosty. I loved to swirl the soft ice cream around in my mouth letting it melt little by little before swallowing it. Then when it was all gone I always wished I'd eaten it more slowly and made it last even longer. I finished the Frosty and returned to visit Ed.

I heard someone pounding away at the piano in the distance as I passed Maria's desk. I figured it must be sing-along time, so I walked toward the dining room, passing some stray residents lingering in the lobby. Carol was sitting on the sofa holding her teddy bear. How heartbreaking to see her rambling through the facility, her little bear always in her arms. Michelle passed by and asked Carol how the bear was. Carol smiled but didn't answer. A new male resident was pacing the floor between Maria's desk and the garden door. He was quite tall, at least six foot, and was wearing baggy denims and a smart turquoise sweat shirt embossed with an American eagle in flight. His pale freckled face was accented by brilliant red hair. I waved as I passed him, but he just stared at me and continued walking.

When I arrived in the dining room, sure enough, there was Jan, one of the activities department members, at the piano, flamboyantly dressed in

a vivid gold, ruby and white paisley blouse, sleeves billowing as her arms flailed and fingers flew across the keys. She was playing a medley of well-known songs and singing with gusto. I really liked Jan. She was lively and energetic, sweet and compassionate. You could tell just by her facial expression and tone of voice that she cared about every one of the residents. That mattered to me more than anything else. When I saw Jan interact with Ed I knew she loved him. And I loved her for it.

There were about a dozen residents sitting at the tables, some alone and some in groups of three or four. Jerry, a dutifully-visiting son, was sitting beside his mother, Edna, who had no idea who he was. She was awake, but her head was hanging down and she was staring at the table as though there were something intensely interesting on it.

Ed, as usual, was sitting by himself. They never told me why he always sat alone, but I kind of thought it might be because he annoyed the other residents somehow. That was probably why I didn't ask. I didn't want to know.

He looked nice; close-shaven and hair neatly combed. I walked over and touched his shoulder to get his attention. He looked up, smiled cheerfully, and told me how beautiful I was. There were no other chairs at his table so I got one from an adjacent table and sat down to keep him company. All the songs Jan played were American 'oldies,' and of course Ed didn't know them – he wasn't in this country when they were popular – but he appeared to enjoy the festive atmosphere anyway. He was smiling and giving Jan his full attention. If she weren't playing the piano, I was sure he'd be telling her how beautiful she was.

"She's the most talented piano player in America," he told me. "She is very famous. Everyone knows her. It is an honor to hear her play. But when she plays, she plays without stopping for four hours. R-r-really. I mean it. She plays for *four* hours! It is *too* long!"

*Some day I'll have to tell Jan that story. She'll get a kick out of it.*

She played a wide variety of songs, mostly from musicals like *Oklahoma*, *Porgy and Bess*, *The Music Man*, *West Side Story*. Things like that. Having run the gamut, she started ripping into some patriotic songs – *God Bless America*, *Born in the USA*, even *The Star Spangled Banner*, to which no one stood. A few residents sang along. Others moved in time, or out of time, with the music. Some sat stoically, as though the music hurt them, while others' heads drooped while they dozed off.

Next she plunged into the Beatles' song, *Yesterday*. I was stunned when I heard the first two lines. I fought back tears and my lower lip quivered. It was true. Yesterday my troubles *did* seem so far away and now it looks as though they *are* here to stay. He isn't going to get better. I was about to burst into tears and sit there sobbing. I looked up at the ceiling and around the room to distract myself. I bit my lip. I didn't want to make a scene in front of Ed, the staff and the other residents.

*How can she play that song when there are family members here with their demented loved ones?*

She kept right on playing and I kept struggling to keep the tears at bay. The words became more painful. It was true. He *wasn't* half the man he used to be. There *was* a shadow hanging over him. If a great poet tried, he couldn't write more poignant words about a demented loved one. I was just relieved Ed didn't know the words to that song, but guessed that even if he did he couldn't make the connection between the words and his current condition. I wanted to go talk to Ann about it but realized I couldn't control myself much longer so I jumped up, abruptly told Ed I had to go, and headed straight for the parking lot.

In my car I lost it. I pulled onto Damon Road and drove home on autopilot, crying all the way. I kept hearing the song in my head over and over. Memories of 'yesterdays' from nearly thirty years before flashed into my mind as vividly as if they were from yesterday – literally: Ed standing tall at the ocean, his Eastern European skin darkly bronzed; Ed elegantly dressed, taking me to exquisite restaurants on New Year's Eve; vacationing at Lake Garda; my Jewish Ed having me decorate his little Christmas tree each year; his delight at seeing the tiny blinking lights.

*How could Jan play that song?*

In retrospect I was sure she didn't link the words to a person with dementia. To a man who wasn't half the man he used to be. Otherwise, she never would have played it. But that realization didn't stop my sorrow.

More memories. Making love on his Kilim when he returned from that one especially long trip to Paris; our pet names for each other, which we used to that day; all the times he sat on the sofa while I stretched out and rested my head in his lap, talking for hours; staying at Harbour Town, listening to the folk singer below our window sing *Puff*

*the Magic Dragon*. I could hear *Puff* in my mind as clearly as if the singer were performing it right then in my car. That made me cry harder.

“There is no greater sorrow than to remember happy days in a time of grief.” Those words from Dante’s *Inferno* never rang as true as they did that day. It was the first time I’d felt the full force of my loss. The first time I’d cried about it. For in all those years I’d never realized until right then just how much I’d loved Ed, and loved him still.

### **Interminable Grief**

I was sinking deeper into grief each day. I had been thinking a lot about grief related to loved ones with dementia. How you lose them, but they’re still there. How many years the grief may last before they finally die, and then you have to begin grieving all over again. Death provides a clear starting point for your grief and you know that eventually there will be an end to it, more or less. But with dementia, loss comes in bits and pieces and drags on and on for many years long before the person even dies.

I found an article on the Internet that said a 90-year-old person diagnosed with Alzheimer’s will live, on average, three additional years. So if Ed lived three more years and if it then took at least three more years to complete the grieving process, grief would consume the next six years of my life. That seemed like an eternity. And who knew – he could live longer than that. I found another article stating that the psychological toll of caring for a demented loved one was so great that most caregivers were actually relieved when the person died. I felt overwhelmed. I didn’t think I’d be able to handle so much grief for an interminable period of time.

One day I couldn’t bear it any longer. I thought it might be less sad to stop reading about grief and start studying caregiver stress. After all, even though Ed was in a facility, I was still one of his caregivers. I found several articles online. One said that many caregivers feel more depressed while caring for a family member with Alzheimer’s than they do after the person dies. Another stated that placing a loved one with Alzheimer’s in a nursing home is no panacea for the guilt and depression many caregivers feel.

I was wrong. The articles about caregiver stress were just as sad as the ones about grief.

Hoping to relieve my depression a little, I decided to go browse at Joseph Beth in Rookwood Plaza for books on photography, my new hobby – the only thing in life then that gave me any pleasure. It transported me to another world. A world where time stopped and there was no pain or sadness – just the joy of being endlessly creative.

As I was pulling an especially heavy book from a shelf I heard a sweet woman's voice saying, "Leave that alone now, Lester. We won't buy that book today."

I turned and saw an elderly couple, the woman probably in her early eighties, wearing a simple gray dress, looking empathically at the man standing beside her. What really hit me unexpectedly was the man, Lester. Probably the same age as the woman, he had a vacant facial expression. His expression, combined with his posture and general demeanor, told me he was demented.

A picture of Ed burst into my mind's eye. I saw him at Alois being pampered by all the loving nurses and aides. I was overcome with sadness as the realization hit me.

Ed didn't need me anymore.

For years he'd relied on me for almost everything. For years I'd probably spent twenty hours a week either with him or running errands for him. But now almost everything he needed was provided by the staff at Alois. And since he only lived in the present, he likely didn't even notice if or how often I came to visit. He probably wouldn't notice if I stayed away for a week or two. Perhaps he wouldn't even notice if I *never* visited him again. I knew he was happy to see me when I was there, but when I wasn't I doubt he knew I existed.

A gigantic vacuum was threatening to swallow me up. I had never felt so unneeded, useless and worthless.

### **The Coach**

It was at about this time that Rosa told me the local Alzheimer's Association Chapter had a free online coaching service for caregivers of Alzheimer's patients, and I decided to sign up. Although I met with Rosa weekly and she provided substantial support, I thought this service could offer additional help because the coaches were *specialized* in helping caregivers of Alzheimer's patients.

I was not exactly adept at using a computer – typical of people in my generation - but after tinkering around on their website a bit I managed



to register, and I anxiously waited to see what would happen. A woman named Marjorie e-mailed me a few hours later, welcoming me to the service. I imagined Marjorie to be an older lady with grey hair and multiple grandchildren. That would make her laugh because I later found out she was a young woman with two small children, and I was old enough to be her mother.

After receiving Marjorie's initial e-mail I mastered the technical procedure for responding, and thus began a beautiful and nurturing relationship that would last more than three years, well beyond the remainder of Ed's life. My initial expectation was that Marjorie would mostly provide practical caregiver advice. I couldn't envision e-mail as a medium that would enable the development of a close relationship that would provide emotional support. How wrong I was. Over the years we grew close even though we would meet in person only once – at Ed's memorial service.

Marjorie became my new strongest supporter for all matters related to Ed. She provided a wealth of information about Alzheimer's disease and issues relevant to caregivers. She recommended books and articles and forwarded handouts produced by the Alzheimer's Association. But she did so much more. She helped me deal with my caregiver stress, the slow but steady deterioration of Ed's physical health, the inevitable progression of his dementia, the issues of whether and when to engage hospice services, end-of-life care decisions I had to make on Ed's behalf, and my emotional preparation for Ed's eventual death. And after Ed was gone Marjorie would support me for nearly two more years as I grieved.

Reflecting on the relationship now, I realize one reason it was so dear to me was that Marjorie shouldered most of the responsibilities Ed had to relinquish as he became demented. She listened and was empathic. She understood and cared. She gave me advice, and it was always good advice. She praised me for my accomplishments and provided encouragement when I needed it. But mostly, she was there for me no matter what. She became my new 'rock.' And for that I will be eternally grateful.

### **The Godfather Goes Silent**

Life with Ed over the decades had been like one continuous phone call with frequent breaks for us to conduct our respective daily life activities.

We'd talked on the phone every day since 1975. Some days we talked only once, but most days we talked several times. Some calls lasted an hour or more; some just a few minutes. He called me. I called him. We talked about whatever topics arose: my job, my friends, my pets; his friends, his travels, his job. Politics, world events, TV shows, movies, and most of all – our feelings. Often he called just to tell me something funny he'd heard on TV or something interesting he'd read in the paper. Or I called to tell him about an exciting development at work or a fascinating aspect of whatever hobby I was pursuing at the time. We talked so much he sometimes told me he had to take a break because his arm was getting tired from holding up the phone.

A few years before he went to the Alois Center I got a new cell phone and assigned him a special ring tone – the *Love Theme from the Godfather*. This made my dear friends, Teresa and Marsha, laugh. It was such an appropriate ring tone because Ed was both imposing and loving. I looked forward to hearing the *Godfather* throughout the day singing out its rich polyphonic sound on my little Sanyo.

In the months right before Ed went to Alois, though, he'd fail to answer his phone occasionally. I could never get him to explain why. Then after he went to Alois the situation got worse. He called me less often and failed to answer my calls ever more frequently. And when he *did* answer we often couldn't connect. The aides reported that he sometimes held the wrong end of the receiver to his ear, or held it in his lap while talking, or put the receiver on the night stand and just went about his business.

I was distraught. I was used to calling him whenever I wanted and talking as long as I wanted as many times a day as I wanted. But it had become nearly impossible to talk to him on the phone at all. While lying on the sofa in the evenings watching TV, I often caught myself reaching for the phone. Then I'd remember and pull back my arm. I couldn't imagine how the situation could get any worse, but it did. He finally stopped calling and answering at all. He'd lost his ability to use the phone so quickly after entering the Center that sometimes I worried that just putting him there in the first place had caused his mental status to decline more rapidly than before.

Then one day I had his phone service discontinued. The *Godfather* went silent and I never heard his music again.

**Filling the Void**

Not being able to call Ed at all – let alone for frequent and long calls – was almost unbearable. I hadn't been aware until then how important those calls had been to me. How much companionship they provided. Even when Ed became demented, talking to him provided some comfort. I did visit, but it wasn't the same as picking up the phone *any time of the day or night* and hearing his heavily-accented deep bass voice – the voice that had attracted me to him in the first place.

Reading about Alzheimer's helped me understand what was happening to Ed, while also helping me make sense of what was happening to me. According to the Alzheimer's Association website, the burden on caregivers is so great that taking care of their loved ones significantly increases their emotional stress and endangers their own physical and mental health. I understood that all too well. I was distressed, depressed, and confused. And I felt utterly alone. Never in my entire life had I felt so alone.

I was especially lonely on weekends. After my Saturday and Sunday visits with Ed, which themselves were boring those days because we couldn't have any meaningful discussion, I came home and lay on the sofa, mindlessly watching TV. I wanted to talk to Ed; my old Ed, or even my demented Ed. I didn't care which. But I knew I couldn't. Just looking at my cell phone on the coffee table brought sadness to my heart.

I had to do something. I knew I could never replace Ed, but I had to find *someone* with whom I could spend time on the phone. *Someone* to help pass the time, especially during the long drawn-out weekends. I had friends, of course, but realized none would be willing to talk on the phone as long or as often as I needed. The only other person I could think of was my mother. I had been calling her every Sunday anyway, but decided to start calling more often.

Shortly before this time Freddie and I had been virtually cut off from talking to mother at all. Mother had always been mentally ill, but after my father's stroke and death she'd begun having more serious psychiatric problems and wasn't able to manage living alone. So she moved in with my brother, and his wife, Diane.

Phillip thought my sister and I aggravated mother's mental condition when we talked to her, so he actually got her an unlisted number and wouldn't give it to us. He called each of us once a week and let us talk to

her for five minutes while he listened in on the extension phone. We were devastated to be cut off like that, and livid with our brother.

Then the situation got worse. After six months Phillip, who had Power of Attorney – *I told mother not to sign that form* - put mother in a nursing home. I don't know exactly why he did it but Freddie and I always assumed Diane had something to do with it. We figured she may have given Phillip an ultimatum – either mother went or she would. But the most incredibly thing was that he adamantly refused to tell us *where mother was*. After a couple of weeks I called around to all the nursing homes in the area and eventually found her at Autumn Years Lodge in Fort Worth. Then Freddie and I called whenever we wanted.

When I decided to start calling mother more often, I called regularly on Wednesdays, Saturdays and Sundays. I loved my mother dearly and would have sacrificed my very life for her, but talking to her on the phone, especially at first, was difficult. We didn't really have anything in common, and it was sometimes hard to find topics to discuss.

Nonetheless, as time went by I realized we were both enjoying our talks and we both seemed to look forward to them. It was around that time that I started sending her weekly care packages filled with little surprises and her favorite candy. I listened carefully during our talks. She'd sometimes mention in passing something she wished she had, like a specific article of clothing or a certain CD. Things like that. Sure enough – without fail those items would show up in the next week's care package. She loved it and I loved doing it.

Mother was often the only human contact I had during weekends. And she was the only person who *ever* said, "I love you." The calls had become something stable to hold on to as I was grieving the loss of my 'old Ed.' She was always there, she always answered the phone, and she always held the proper end of the receiver to her ear. Plus, she never tired of talking to me and I was gratified that I was giving her companionship as well. What had started out with the mere desire to fill a void had become a tremendous chance to reconnect deeply with my mother.

A grave thought surprised me one day. *What on earth will I do when she's gone?* Loss – both present and anticipated – was becoming a poignant theme in my life.

**Inconsolable**

Then one day I hit the lowest point in my life. It started with my alarm clock blaring at 5:30 AM, jarring me awake from a dream in which Ed was no longer demented. I'd been having that dream a lot. A searing pain burned in my chest the instant I became aware it had only been a dream. I fumbled around in the darkness until I found the snooze button, which I pushed. Then I pulled the blue wool blanket up over my head and instantly fell back asleep.

The alarm went off again five minutes later, startling me again with its loudness. The pillow was comforting and I didn't want to lift my head from it, but I forced myself to get up anyway. I raised the bedroom blinds only to discover they'd been hiding ominous-looking dark clouds and a heavy rain. I grabbed an umbrella and took Peter out. Although I usually dried his paws when I brought him back in from the rain, I didn't have the energy to do it. I made a cup of coffee, which I drank while sitting slumped over on the edge of my bed, all the while feeling utterly depressed.

I was inconsolable, thinking about my visits to Ed. Truth be told, I was beginning to dread going at all. I was bored during my visits, which seemed to drag on for an eternity. I was usually moody and sat mute, listening to him repeat his monologues ad infinitum. Then I'd leave, feeling terribly guilty, depressed, dejected and unloved.

I had taken that day off because Teresa was coming down from Dayton to celebrate her 35<sup>th</sup> birthday. I was going to surprise her by taking her to lunch at the Celestial, with its breathtaking view of the river. But I was so depressed I didn't want to see anyone, not even Teresa, so I reluctantly called her and we rescheduled. After a long sigh I lifted Peter into my bed and crawled in with him.

I felt so terribly guilty. Ed was the man who had given so much of himself to me for so many years. How could I visit him only out of a sense of duty – not love? My friends had told me to try to 'reach' him by looking at old photographs together or watching TV shows he liked together. There were times when I resented people suggesting I focus on finding a way to reach *him*. Couldn't they understand I also wanted him to reach *me*? These thoughts were, of course, terribly selfish, but Ann said all Alzheimer's caregivers have these feelings at times and I wouldn't be normal if I didn't. And the Alzheimer's Association website, which I'd studied so much I'd virtually memorized parts of it,

stated that caregivers can feel grief, anger, guilt, depression, resentment, and exhaustion. Well, that just about summed up my mental state.

I got up around noon and took a shower, standing motionless under the tingling hot water for more than fifteen minutes, feeling a sense of total inertia. I finally got out and put on my bathrobe and slippers. I resisted the urge to go back to bed. Instead I dragged the blanket from my bed out to the sofa and spent the afternoon there with Peter snuggled against my chest. I tried watching *Driving Miss Daisy*, but thoughts of Ed kept occupying my mind, obliterating everything on the TV.

Around 5:00 PM I got up long enough to gobble down a pint of Graeter's chocolate chip ice cream, take Peter out into the steady downpour, then return to the sofa. Throughout the evening my eyes were periodically drawn to my Sanyo, sitting on the coffee table as useless as if its battery were dead.

### **Duty Calls**

Just as I was getting ready for bed that night the phone rang. I glanced at the clock. It was 10:00.

*Who could be calling at this hour?*

I picked up the phone and was shocked when I heard mother's voice.

"Marie, you better come down here," she said loudly, her voice quivering.

"Why? What's going on?" I asked, alarmed by her tone of voice.

"I've been bleeding 'down there' and I'm supposed to have an Ob/Gyn procedure Wednesday but Diane cancelled it. Can you come down here and fix it back?"

She sounded near tears.

"Why did she cancel it?" I asked.

"Because the doctor is Indian. Diane says I don't need it. That the doctor's just doing it to get the money."

I cringed. Diane was so prejudiced. She didn't trust anyone but Caucasians.

"I really need this surgery," she said, beginning to cry. "I'm bleeding. I may have *cancer*."

I was worried about going. Phillip still didn't know I'd even found out where mother *was*. And he certainly didn't know that Freddie and I had been secretly calling her. If I went down there he might get her another

unlisted number and we'd *never* be able to call her again. But she probably did need the surgical procedure. I *had* to take the chance.

"Okay, mother. I'll come tomorrow," I said, getting a Nicorette off the night stand.

I felt a rush of adrenaline that overpowered my depression at least for the time being. Phillip had the Power of Attorney, and somehow I was going to have to trump that to get the surgery reinstated. I had no earthly idea how I was going to do that.

Early the next morning I called Autumn Years Lodge and spoke to the head nurse and explained the situation. I was clenching my fists as we talked.

"Oh, Ms. Marley," she said in a most friendly tone of voice. "The Power of Attorney only comes into play if your mother is mentally incompetent, and no such determination has been made. So you just come on down and take care of it. Your brother can't do *anything* about it."

"Really?" I asked.

"Absolutely!"

I unclenched my fists.

During the two-hour plane ride I kept thinking about my previous visit to Fort Worth. It, too, had been an emergency. It was when my father had his stroke and was in a vegetative state, in which he'd remained for more than a year before he died. He couldn't talk, so mother just sat there and held his hand for an hour every day, talking to him and convincing herself that he knew she was there and understood what she was saying.

When I visited that time I sat stiffly in a chair beside his bed for fifteen minutes each day I was there, periodically saying in an inappropriately cheerful voice, "Hi, daddy, I came to visit you." I felt morally obligated to visit, but ever since the violence of my childhood I'd felt intensely uncomfortable just to be in his *presence*. There was no way I was going to *touch him* - hold his hand like mother did. I'd tried mightily over all the years, but had never been able to forgive him. Of course I hated to see him like that, yet there were fleeting moments when deep in the darkest, most evil recesses of my soul, I felt his present state might be a fitting recompense. But I always instantly concluded that not even *he* - not even such a *brutal* man - deserved to end up like that.

Shortly after I arrived at the nursing home, mother and I went to meet with Lori, one of the nurse supervisors. She was very tall with short curly dark hair, and was wearing blue scrub pants and a white smock with blue and pink kittens on it. During the meeting she had mother sign and date a statement saying that she wanted the surgery, and then I called and managed to get it rescheduled for the following day.

The next morning I took mother to the hospital and sat anxiously in the waiting area until the surgeon came to talk to me. She said she'd found and removed a polyp, which she said was probably the cause of the bleeding, and that she'd call me in a few days with the pathology report.

Mother and I had a great time during the rest of my visit. I took her to an Italian restaurant, Scotti's, that evening and to a movie the following afternoon. My last night there we visited in her room with one of the young girls from the activities department and we laughed ourselves silly. I hadn't laughed so hard in years, and I'd *never* been so happy to see my mother laughing.



## Chapter 10: Love Endures (2006)

### The Little Yellow One

Two days after I got back from Texas I was headed to the Alois Center for what I assumed would be another boring visit. The gloomy rain and dark clouds matched my mood as I backed out onto Sterling. It had been raining all morning. The kind of steady downpour that invites one to stay inside all day, curled up with a good book and a cup of hot tea.

I was depressed and guilt ridden, as always, because I really didn't want to go. Before going I had to drop by Walgreen's to buy some shampoo. I was completely out and had used bar soap that morning. To get the shampoo, I had to pass the stuffed animal section, full of darling creatures sitting willy-nilly on the shelves, just waiting for little children to pass by and beg their mothers to buy one.

I had no idea why, but those sweet little playthings caught my eye and brought Ed to my mind. *Would he like a stuffed animal? He was childlike at times.* I immediately told myself I was crazy and that he'd feel insulted and become irate if I gave him a stuffed animal, thinking I considered him nothing more than a child. So I left that area, resolutely heading for the hair-care section, wondering how I could be so ridiculous as to even *think* about getting Ed a stuffed animal.

I got the shampoo and picked up some conditioner and tissues while I was at it, and moseyed toward the cash register – I wasn't really in a hurry to get to Alois – when suddenly my heart told me to go look at the little ones again. So I walked back to their temporary home, all the while telling myself I was nuts. But they *were* cute. There were bunnies, chickies, duckies, teddy bears, and others whose classifications I didn't know. I stood in the middle of the aisle – or 'ail' as Ed pronounced it – and argued with myself. On the one hand, I could envision Ed playing

with a little stuffed animal, happy to have such a cute toy. On the other hand, I was convinced he'd get angry and tell me to go to hell.

*Why was I even standing there pondering that absurd idea?*

Finally, on a whim and against my better judgment, I decided to buy one. I selected the tiniest one they had, thinking that if he got angry he'd be less angry over a smaller one than a bigger one. I chose a miniature yellow chick. Five inches tall, it had a pale pink bow tied around its neck, a bright orange beak, matching orange webbed feet, and tiny black plastic eyes. When you pressed a little red button on its chest it said "peep, peep, peep." At the cash register I felt silly, even though the clerk, a sullen overweight teenaged girl with blue fingernail polish and a pierced nose ring, couldn't begin to guess a 93-year-old man would be the recipient of the purchase.

On the way to Alois I wondered if Ed would yell at me. What was any 93-year-old man, let alone *my* 93-year-old man, going to do with a stuffed animal that peeped? That former erudite scholar and lawyer, a man who'd had such a brilliant mind?

Once at Alois, I stopped at Maria's desk before going to Ed's room.

"Hey, Maria," I said, showing her the little chick and pushing the red button, making it go "peep, peep, peep." "I got this for Ed. Do you think he'll like it?"

"Oh! What a cute little thing! He'll *love* it. I'm sure."

"I don't know about that. I hope he doesn't have a fit and yell at me."

"No," she said, smiling. "He'll absolutely love it."

"You know what, Maria? I doubt your judgment as much as I doubt mine."

We laughed. As we were talking we saw poor bent-over Mr. Brooker pass by wearing a business suit that day, and a serious expression on his face after his daily three-hour visit with his wife. I hadn't met her yet, but assumed she'd been asleep the whole time. As I did every time I saw him, I worried how on earth he'd spend his time if she died before he. I fervently prayed he'd go first. I figured she might never know the difference.

I told Maria good-bye and began walking through the lobby, where I came across George, wearing cargo pants and his same old baseball cap with an embroidered fisherman on it, giving him the semblance of a rough outdoorsman. He was gruffly muttering at another resident. Yep, that was George, alright. Ever true to himself. Michelle told me they'd

been 'working with him' on his behavior. I guessed he was better because he soon stopped the menacing and went back into the lobby. As I passed I didn't speak to him. I usually spoke or waved to the residents I passed, but I always ignored George – probably because he was mean. I supposed he had a good heart like most of us, he just didn't show it that much any more. And he probably had a family who loved him as much as I loved Ed. I really shouldn't have been so prejudiced. I had been quite surprised when I'd found out George had been a teacher for special needs children.

I made my usual brief detour to the vending area and got my Diet Coke and Snickers. I always felt guilty eating and drinking in front of Ed but I was selfish enough to do it anyway. Besides, he never seemed to notice.

Passing the dining room, I saw a few residents still sitting there. Carol, teddy bear on her lap, was eating. Edna was staring at her food and picking at it with her fingers. A third resident whose name I didn't know was sort of slumped over her empty plate. Ed wasn't there so I assumed he'd finished and gone back to his room. I walked down the hallway, swinging the little Kroger's bag back and forth and feeling self-conscious, as though each resident I passed could see through the bag and know I was going to get in trouble. That was ridiculous of course. Even if those demented residents could see what was in the bag they'd never connect it to me possibly getting yelled at.

I found Ed sitting on the sofa and looking out the window. When I greeted him, he quickly turned toward me and said he was delighted to see me. He then delivered his monologue about how beautiful I was and his other monologue about how lucky he was to have my presence. I sat down beside him, feeling both anxious and silly. I took the chick out of the bag.

Summoning up all my courage I said, "I brought you a present today, Kitty."

I held the chick for him to see, then handed it to him. I knew in my gut he was going to be angry so I braced myself for the onslaught, but at first he didn't react at all. He just sat there looking at the thing. I wondered what was going on in his mind. His facial expression was blank.

I didn't have to wait much longer. His reaction shocked me, to say the least. His eyes sparkled and a look of wonder came over his face. He

gazed at me as though I'd just given him something magical. I showed him how to push the little red button. The chick went "peep, peep, peep." He looked at me again as though he'd just witnessed a miracle. His eyes shone and he started laughing and pushing the button repeatedly, putting the chick to his ear each time. Then he held it by its little feet with his left hand and began stroking its back with his shaky right hand.

"Kitty, I can't enough thank you," he said, smiling radiantly as he continued petting the chick. "You help me so much and now this wonderful puppy you brought me."

He called all stuffed animals 'puppies.'

"And I really meant it. It's from my heart, not just words from my lips," he said, using his stock phrase.

"I think you should give it a name," I said.

"The Little Yellow One!" he announced with glee, as though that was the one and only name it *could* have. "He's wonderful. I'm so happy to have him with me here."

"I'm coming to visit you again tomorrow," I said, changing the subject.

"Oh! I'm delighted!" he said. And then he asked, "Do you know who else is delighted?"

"No. Who?"

"The Little Yellow One!" he said.

It was clear he was aware and proud he'd said something amusing.

I was always astonished when he had those moments of lucidity. They were even more touching when he was humorous.

Hearing how much he loved The Little Yellow One, I decided to take a chance and ask, "Would you like to have a bunny rabbit, too?"

"Oh, yes! I would love to have a bunny r-r-rabbit because he would be for the Little Yellow One a companion."

I decided then that if stuffed animals gave him so much pleasure maybe I'd keep bringing him little childlike presents and maybe even start interacting with him as though he were a child. It wasn't the kind of interaction I'd been wanting, but it was better than sitting in silence, feeling dejected and bored stiff.

Just before I left Ed looked at me and said, "Sol omnibus lucet – Petronius."

"What's that mean, Kitty?"

“The sun shines on all of us.”

I was amazed he still remembered the Latin sayings he'd always loved to throw into his speech. This one, however, would be the last I'd ever hear him say.

On my way home, I felt joy that I'd brought him so much joy with the little chick and I was proud I'd been brave enough to take a chance on getting it. When I neared my house, I realized that this visit hadn't been boring and the drive home hadn't seemed long as most.

### **Adorable**

I knew Ed was going to be overjoyed during my next visit. Not only was I taking a bunny rabbit as promised to be a companion to The Little Yellow One, I was also taking Peter – ‘Pe-tair’ as Ed called him. I wondered which animal would bring more joy. If I had to guess, I'd say ‘Pe-tair,’ because he returned Ed's love.

Peter scampered down the hall pulling on the leash. He'd been there so many times he knew which room to enter. He ran to Ed, who was sitting in the rocking chair staring into space, and startled him by jumping up, putting his front paws on Ed's knees and licking his hand.

“Oh!” Ed said.

When he recovered from the surprise he said, “‘Pe-tair!’ The *little* one. He's adorable. I love him so much!”

“Peter. Get down,” I commanded, knowing full well Peter would not obey. He never obeyed that particular order.

“Kitty, can I hold him?”

“Sure,” I said. “I'll put him on your lap but you know he won't stay. He always jumps down and comes to lie at my feet.”

“Maybe he will this time stay,” Ed said, sounding optimistic.

I picked up the *little* one and deposited him in Ed's lap, then sat down on the sofa. Peter was all excited, wiggling around and licking Ed's face. His tail wagged in a blur as Ed patted his head.

“Oh ‘Pe-tair.’ *Little* ‘Pe-tair.’ Let me see your face. Yes, ‘Pe-tair.’ Hold still so I can see you.”

Peter didn't obey Ed any more than he minded me. He continued wiggling around and kept licking Ed's hand. Then with no warning he jumped off Ed's lap and ran to me. He then put his paws on my knees and looked at me as though he were expecting a treat. I petted him and told him to lie down, one of the few commands he typically *did* heed. He

didn't exactly *lie* down but he did *sit* down, though his tail never ceased its motion.

I lifted my gaze to Ed. "Sorry, Kitty," I said, hoping he wasn't too disappointed. "He always does this. I think he's afraid I'm going to go off and leave him here."

I decided it would be a good time to give Ed the bunny. About three times the size of The Little Yellow One, the bunny was light honey-colored with big floppy ears and a white tail. I took it from the bag and handed it to him. He marveled at it, turned it all around, and petted it. Then he named it Adorable and thanked me profusely for bringing him such a wonderful present, "in addition to the present of your presence here, which to me means so much."

*Wow, he's even lucid enough to make a play on words today.*

No one observing us would have guessed Ed was demented, although they would certainly think it odd a man his age was so drawn to a stuffed animal.

Before leaving, I put Adorable at the foot of Ed's bed and stopped a moment in his bathroom. Peter, as always, insisted on going with me. When we came out the bunny was on Ed's pillow. It was so touching. I'd expected him to be attached to Peter but who would have thought a 93-year-old demented man would relate to little stuffed animals on such an emotional level?

I felt warm and connected to Ed all the rest of the day.

### **The Mega-Bunny**

I decided to go wild and get Ed a *really big* stuffed animal – another bunny – the following week. Even though he loved the tiny chick (The Little Yellow One) so much and loved the larger bunny rabbit (Adorable) just as much, I was still a little hesitant because it seemed silly to get a gigantic stuffed animal for a man Ed's age. I was still afraid he'd be irate. Nonetheless, it had worked before and I decided to try it a third time.

I got that bunny at Kroger's since I needed to go there anyway to get some Nicorette. Theirs was cheaper than that at Walgreen's. It was a bright Saturday morning and the sun gently warmed my car, putting me in a cheerful mood as fluffy white clouds floated across the sky in a never-ending gentle procession. The parking lot was swamped, looking like a car dealership lot. I wondered if it was worth saving a few bucks,

but then I saw a dark blue minivan backing out of a space near the entrance. I parked and sauntered into the store. Once inside I found the toy section and reviewed the stuffed animals. They sat at attention just like those at Walgreen's, but the selection was far better. I picked a bunny rabbit about eighteen inches tall with more detail in its design than the other two 'puppies' I'd gotten for Ed. It was pale tan with white arms, legs and jowls, a pink nose and large black plastic eyes. Like the other bunny, it had long floppy ears and a white tail.

I drove to Alois, the big bunny lounging on the front passenger seat, *sans* seatbelt, one floppy ear spilling out of the bag. As I got closer to the Center I felt as hesitant as I'd felt about giving him The Little Yellow One. I didn't even bother asking Maria her opinion. Not only did I feel nervous about Ed's possible reaction to this mega-bunny, I was afraid Maria might actually laugh at me too, so I just smiled and waved as I passed her desk.

On my way to the dining room I came across Tom. He was wearing his favorite yellow sweater vest, tan dress pants and Rockport shoes. Just to look at him you'd never guess he was demented. With most of the other residents there you could easily tell. They had some peculiarity in their dress, hair, facial expression, gait, or just something in their overall demeanor. But Tom seemed like an ordinary person, like a visitor who was there to see a loved one. Only thing was, he didn't know where he was or what he was doing there. Tom used to own a ski resort in Vail. He'd moved to Cincinnati several years before to be near his son, Alex, and had been at the Alois Center for nearly a year. Alex often brought his Golden Lab when he came to visit. Tom nodded as I passed, and I waved at him.

I stopped at the vending machine as usual, then looked into the dining room where a sing-along was in progress. Ed was sitting alone, looking at the newspaper. I could smell popcorn, which Jan must have made for the residents. She was just cleaning up the last of the tables, whisking spilled popcorn into a damp cloth.

I'd brought some of my photographs that day to show Ed, and since Jan was so artistic I waved at her to come over and look at them. She was impressed by my creativity, and especially enjoyed the pictures I'd taken of orange, hot pink, white and yellow Gerber daisies against a black background. I'd removed the stems with my photo editing program, and they looked like fireworks made from flowers. She tapped

Ed on the shoulder and when he looked up told him loudly – the only way he could hear considering his hearing deficit – how handsome he looked. He smiled, thanked her and, of course, kissed her hand.

“Kitty, I can’t understand the newspaper,” he said when she left.

He pointed to the front page as I sat down beside him. He had a bewildered look on his face.

“There are too many stories. There’s so much information here. It confuses me. Look here at this story,” he said, putting his shaky finger on the top left-hand column. “And then this one,” he said, pointing to still another column. “There are so many stories r-r-right here the front page. I have been all morning trying to r-r-read it, but I can’t. I am so ‘meexed’ up. In fact,” he said, looking despondent, “I am so confused I wonder if I should go to a facility for people with mental problems.”

His statement was so eternally sad.

Ed would soon lose the ability to read – except for a greeting card or a stray newspaper headline here and there. In fact, I’d soon cancel his subscription to the *New York Times*. I was saddened even more when I remembered that Julie, one of the nurses, had told me she used to stop in his room in the evenings sometimes and have him read the paper to her. She told me she often teared up when he’d pronounce long words perfectly (except for his accent) and with no hesitation.

I decided to distract him from the newspaper problem, so I flashed him a smile and said, “Let’s go down to your room. I have a present for you!”

We walked toward his room, he resolutely pushing his walker, feet slapping down on the carpet while I walked slightly ahead, swinging my oversized Walgreen’s bag in my left hand and holding my Diet Coke in my right. On the way we passed Albert, his sweat pant leg half way up to his knee. I’d seen him like that before and always wondered why his pant leg was like that. I was sure the aides didn’t dress him that way.

Albert looked lost and as we neared he asked, “Where’s my house? I have to go home and babysit the children.”

“I don’t know, Albert,” I answered. “I bet the aide could tell you. She’s just down the hall. You see that lady in the blue striped blouse? Ask her.”

Albert went down to the aide and they started talking. I didn’t know what they were saying but she put her arm around Albert’s shoulder and they began walking back up the corridor.



Ed and I continued down the hall, passing Ann walking alongside a couple to which she was obviously giving a tour. It reminded me of the numerous tours Ed and I took before he finally agreed to move. After we reached Ed's room we sat down on the sofa and I gave him the bag. He took out the huge bunny and, as with The Little Yellow One, initially showed no reaction whatsoever. That worried me, but soon his face came to life.

"Wonderful! Superb! How beautiful! Kitty, you bring me such wonderful things!" he said, all the while petting the bunny. "I can't thank you enough for everything you do for me. You r-r-really help me so much and give me so much guidance. I can never thank you enough. What a superb puppy! What a talented artist made this puppy. What a superbly talented and original artist made this puppy. My first inclination is to kiss him."

"Go ahead and kiss it," I said, pointing to the bunny's face, giving him permission, as it were, to kiss the bunny.

And he did. Then he continued petting it and talking about it, saying over and over what a talented artist made it.

"Maybe I am ridiculous at my age," he said reflectively after kissing the bunny again, "loving this puppy so much and holding him and kissing him, but I really do love him. I never had such a lovely thing in all my life. Thank you so much, Kitty."

### **The Beep Game**

I rushed into the Alois Center dripping wet. It was raining so hard I got soaked just coming in from the parking spot closest to the door. It had been a sudden downpour and I'd gotten caught without an umbrella. The hood of the slick aqua blue jacket I'd bought at Wal-Mart the previous week kept my hair dry, but the jacket, my pants and shoes were all drenched.

*I really have to start keeping an umbrella in the car.*

On my way down the hall I ran into Rick. Rick was one of the most fascinating residents. He seemed so normal I honestly couldn't understand why he was there. They'd even given him the code to the door and he came and went from the Assisted Living unit any time he wanted. He was hiding well whatever was wrong with him or else his family just dumped him there. I couldn't imagine the latter, because

Alois would never accept a person who wasn't demented. Once Rick told me he'd been there eleven years. I found that hard to believe, too.

Further down the hallway I came upon Linda. You could almost always find Linda walking up and down the hallway and around the perimeter of the Assisted Living areas. She was not as lucid as Bob, but didn't seem as demented as Ed. She wore summer clothes every day, her typical attire consisting of starched white, ironed Capri pants with boldly colored tops – magenta, burgundy, or dark teal – and white crew socks under spotless white tennis shoes. A kelly green golf cap perched atop her silver hair completed her daily outfit.

An interesting thing about Linda was that she had a 'babysitter,' Lois, a middle-aged African American lady paid by Linda's family to stay with her during the day. Lois usually just sat in Linda's room knitting or in the living room watching TV with Linda. It seemed unnecessary, but I assumed Linda enjoyed the extra companionship. I remembered one day when Linda stopped me in the hallway, eyes shining, and cheerfully told me that I was beautiful. She made my day even though I knew she was demented and possibly didn't have the best judgment about things beautiful.

Before leaving my house that day I'd concocted a splendid game to play with my little boy. I started the visit by handing him one of his numerous stuffed animals, an act that always made him smile. I reviewed his growing collection and selected Adorable for the purpose.

"Oh!" he said, his face shining as he stretched out his arms to take Adorable. "Oh! The *little* one! I love him so much."

Come to think of it, that was exactly the phrase he always used when talking about Peter. He put Adorable to his face and kissed him. And, as always, it was as though it was the first time he'd ever seen Adorable.

Suddenly I pressed Adorable's nose and said "beep" at the same instant. Just as I'd hoped, Ed thought Adorable said "beep." He looked at me and his eyes widened as he marveled at the bunny's new ability. Then *he* pressed the bunny's nose and I went "beep" again. He laughed, pressed the Adorable's nose repeatedly, and I went "beep" each time.

He laughed more, then turned to me and said, his voice full of wonder, "Listen what he does, Kitty."

He pushed Adorable's nose and I said "beep."

"No, Kitty," I said, laughing, deciding to reveal the secret. "*I'm* saying 'beep' – not Adorable."

“Oh!” he said. “You are wonderful. You are great. You are superb to make this “beep” just when the bunny’s nose I press!” He then exclaimed loudly and emphatically, “You could ask a hundred people and they would all say you are magnificent.” He then repeated that sentence verbatim.

Next he tried to trick me. He pushed the bunny’s nose several times in a row very fast. I managed to keep up, saying “beep” each time. Then he suddenly slowed down, still trying to fool me. *He is really alert today.* Then he picked up The Little Yellow One and we played the same games with him. Ed kept praising me for being ‘so magnificent.’ We giggled like a mother and her two-year-old playing together. It was fun. As I was leaving he asked when I was coming back.

“Soon,” I said.

“Oh! Kitty. I’m so happy when you come back soon!”

### Acceptance

One morning I realized I was actually *looking forward* to visiting Ed. A profound change had taken place in me. I no longer felt bored, dejected, unloved and unloving during my visits. I enjoyed them and left feeling emotionally satisfied. It was clear I’d had a dramatic change of heart. And what was more, I could pinpoint the day it started. It was the day when, on a whim, I took Ed the miniature chick he’d so proudly named The Little Yellow One.

When I experienced his joy when playing with that tiny stuffed animal my heart began to be transformed. Gradually my need and desire for my ‘old Ed’ began melting away as I realized that I could bring joy to my ‘new Ed’. That man who had lost so much was in a state of childlike bliss thanks to my small gift. His fervent gratitude for the many little stuffed animals I later took him, the fun he had playing with them, and his joy with the ‘beep game’ and other little games I subsequently invented, all made me feel joyous, too. I realized that little by little and without noticing, I *had* accepted his illness and I *had* found new ways to relate to him, ways that were genuinely satisfying for *both* of us. Just seeing him smile and hearing him laugh had become more than enough to make up for losing our previous relationship. My heart had changed forever. Our love had endured, despite that last and most daunting obstacle it would ever face.

## Chapter 11: 'Making Luggages' (2006)

### **A Man's Belongings**

I discovered a large manila envelope with 'Kitty' scrawled on it in Ed's shaky handwriting, the ink faded after what must have been decades of sitting in that box. I'd decided to start what would be a months' long project of sorting through Ed's belongings one Saturday afternoon. It was just a preliminary step in putting his final affairs in order – 'making his luggages,' as he would call it. I was shivering in the November cold in Ed's unit at Oakley Storage. Since I'd considered the previous day's moderate temperature when I got dressed that day, I wasn't adequately prepared for the frigid temperature. I should have worn my winter coat but had just put on my black and red plaid lumberjack's cotton shirt before running out the door.

I began by inspecting nearly twenty boxes of old papers, each releasing a stale smell as I opened it. Then a quick peek told me the envelope I just picked up was filled with cards and letters I'd sent Ed. From the looks of it the envelope must have contained everything I ever sent him. I knew Ed kept 'everything,' but it never occurred to me that included all of my cards and letters. Realizing he did warmed my heart and made me realize more than ever how much I must have meant to him over the years.

There were also some photographs, staring at me from the past, in a small envelope inside the larger one. I was filled with excitement just seeing those treasures, but I wanted to finish my work before looking at them, so I walked outside and tossed the envelope into the back seat of my car. I'd wait until I got home to examine those precious things, savoring each as pleasant memories would, I was sure, be brought to mind.

I sighed with relief when I finally finished going through the boxes of papers, most of which I put in the dumpster. My next task was to review

several boxes of clothing that had been packed by the movers when Ed went to Alois and no longer needed so many clothes. I suddenly found the mortarboard, looking brand new, from his doctoral 'cap and gown.' I wasn't prepared for that and felt light-headed as I pictured Ed at the height of his intellectual prowess marching to the stage to receive his doctoral diploma. It was especially poignant when I compared that to his state of mind at the time. It was strange how one could hold up in the face of enormously sad events only to be overcome at an odd moment by some trifle like that. I felt tremendously sad but forced myself to stay in control. I had a job to do.

I took a short break then started working on the clothes. Many reminded me of Ed back in the 'good old days,' back when he was always dressed so stylishly, which only saddened me more. I decided which to give to charity and which were too worn to even give away. Finally I started looking through five large boxes of vases and other home decorations, all carefully wrapped, or at least as carefully as Ed could wrap them in his demented state. He'd insisted on packing these items himself instead of letting the movers do it. Some had monetary value, some only sentimental value; others had neither.

There was one item I especially wanted. It was a gorgeous piece of deep red heavy fabric with intricate hand embroidered black and white geometric designs on it. Measuring around 18" by 24", it had long red tassels on all four edges. Ed had folded it in half and used it as a runner on one of his lamp tables. I'd always loved it and had my heart set on having it. But I wished I'd gotten it under different circumstances.

So that was the fate of a man's lifelong collection of possessions – being sorted through, unbeknownst to him, by a loved one in a stark rented storage facility. Some put aside with care, others deemed worthless and tossed into the trash with hardly a thought. Items purchased only after long consideration and with hard-earned money discarded after split-second decisions.

I finished with all the boxes then headed home. On the way I passed Nick's Chops & Chasers, one of the restaurants he used to take me to. We'd gone there early on when we were lovers. Continuing down Madison Road I passed Vielhauer-Clepper, where I would eventually have to go to prearrange Ed's cremation. It was as if a lifetime had passed in the mile or so between those two establishments. My heart sank. I wasn't ready to let go. Not at all.

**Treasures from the Past**

When I got home I was so excited about delving into the big envelope that all sadness was gone. Peter settled on my lap as I opened the envelope and spilled the contents onto the coffee table. Scanning the pile briefly, I found that only two items bore dates. One was from 1982, when I was 32 and Ed was 69; the other was from 1993. Both were years after our romantic relationship had ended. I had no idea if any of the other items were from the years when we were lovers, but it didn't matter. Our *affect* toward each other hadn't changed that much.

Most of the cards were cute and childlike, revealing a young woman's immature infatuation – first with her older lover, assuming some dated from that time, then with her life partner. Ed had paid me to type stuff for him and I found some cute bills from "Kitty's Typing Service, Kitty Black, President." One had a note: "We accept cash, check, money order, or Meow Mix." I smiled, remembering how much I'd always hated typing for him because even after I'd start he'd keep changing his mind about what he wanted. Yes, we had many fights over "Kitty's Typing Service."

I also found a series of cute miniature cards, approximately 2 1/4" by 1 1/2". As I was starting to study them the phone rang. It was a nurse from Alois, who told me that Ed had just fallen in the dining room but that he was okay. I was alarmed and asked her if she was sure he was okay. She assured me he was. That news disturbed me immensely. It was so incongruous to know Ed had fallen and could have seriously injured himself while I was looking at silly little cards. Nonetheless, a few moments later I managed to stop worrying, let go of the present and slide back into the past.

***Aria***

As I dug deeper into the pile I was shocked when I found a piece of prose I'd written when I was in my late 30s. I remembered Ed was extremely impressed with it so I wasn't surprised *he'd* kept it, even though I hadn't kept a copy for myself. It was obvious that I'd written it during one of my deep depressions. Rereading it made me understand that suffering can be beautiful, even if one doesn't realize it at the time. Although I didn't intend it so when I wrote it, I saw it could fit as a description of part of the grieving process.

*Aria*

I wish I were an opera composer. I would write the saddest opera of all time. Then find the greatest voices in the world to perform it with the best orchestra in a perfect hall with the most appreciative music-loving audience.

They would listen intently to every note, every chord, each inflection. And they would cry. For some, just a few tears would fall ever so slowly down their faces – as though their tears could fall to the rhythm of the *adagio* aria. Others would cry openly, Italianately, with arms outstretched as though to comfort the characters on stage.

But that's the saddest part of all. The audience cannot comfort the characters. They can only feel their pain and share it and cry themselves. They cry because the music reminds them so strongly of their own pain. Their own losses. Their sorrow. And tears. Sadnesses past and present. The music reminds them of pain they have felt, pain they feared, pain they imagined, pain dreamt about, pain recalled from dreams. The pathos of every sad face they have ever seen. Now it is all expressed in one perfect, beautiful, exquisitely painful and sublimely sad aria.

It will end. The aria will be over. The opera will reach its finale. The audience will go home.

And remember.

For awhile.

They will suffer while hearing the aria repeatedly throbbing in their minds. Demanding their attention. Driving out any other thought or feeling. Then they will sleep. And be comforted by rest and by dreams of angels who will soothe their pain. They will awaken and remember their dreams. They will feel sad still, but less. They will remember the aria at an odd moment during the day, and cry again. But briefly.

And I, the composer, will then – and only then – be able to stop crying.

**Spiraling Downward Day by Day**

Ed was on a fast day-by-day decline.

**October 3:** Ed was getting out of breath just sitting in a chair. I started to wonder if it might be time to begin putting his final affairs in order, or ‘making his luggages’ as he would put it.

**October 4:** Ann was right. Just when you accept their condition and feel like you can handle it, they get worse. Things had been calm and tranquil for awhile, but Ed's care conference brought bad news. His decline up to this point had been primarily in his mental state. Now his physical health was deteriorating. He needed more and more nursing care and sometime soon (not *immediately*, they'd stressed) he'd have to move to the Terrace, the next level down, a unit where he could receive more care and be in a quieter environment.

This was serious. I was so upset that at one point I realized I was holding my breath.

**October 11:** I was blindsided. I got a call from Ann a week later. She told me a room had opened up in the Terrace and they wanted to move Ed in two days. *In two days? But they had said the move wouldn't be 'immediate.'* I wanted to protest, but knew no protest in the world could stop the downward spiral of Ed's health.

The Terrace was the third lowest of their four units. In my mind this was a foreboding move and meant Ed had taken yet another step closer to the end. There was just one more level down, the Gardens, and not all residents lived long enough to ever make it there. I started referring to it as ‘the place where Alois Center residents go to die.’

**October 12:** The phone rang the next morning just as I was getting out of the shower. I threw on my raggedy pink terrycloth robe, to which I'd long before lost the belt, forcing me to hold it closed with one hand while I answered the phone with the other. It was Michelle, calling to say that the Medical Director, Dr. Zakem, had ordered a test to see if Ed had congestive heart failure – CHF. CHF was serious and incurable, and it was especially ominous for someone Ed's age.

**October 13:** “I want to go home,” Ed kept repeating plaintively to me and everyone who passed by.

He was sitting on a little padded bench outside his new room. He looked bewildered. I felt faint and terribly guilty. I felt as though I'd ripped him away from everything that had become familiar to him. From what he had come to accept as his ‘home.’ I couldn't begin to



imagine how confused and lost he must be feeling, and there was nothing I could do to make it better. Seeing my tearful state, Janelle, the Terrace aide who would soon become my favorite, looked at me with compassion, squeezed my hand and said, "He'll be okay. You'll see."

I would soon learn that the aides in the Terrace were the most empathic of them all.

On my way home, instead of turning onto Sterling Way, I kept driving up Marburg to Erie, where I ducked into the UDF and bought a pack of Salems. Then I headed home. The first thing I did was smoke one. The second was break all the others into pieces and flush them down the toilet.

*I am not a smoker.*

**October 14:** The instant I woke up I heard Ed's melancholy voice in my head, repeating over and over, "I want to go home." It brought great sadness to my heart.

I drove to Alois with a new stuffed animal, hoping it might bring Ed some comfort. I ran into Janelle outside Ed's new room. Dressed in teal scrubs that flattered her mocha skin, she had black hair that was very intricately woven. She also had an ever-present radiant smile – a smile so serene I always assumed it was spiritually inspired.

"How's he doing today?" I asked, expecting the worst.

"Oh, he's fine," she said with a little laugh. "He's stopped asking to go home."

"He *what?*" I asked, stupefied.

"Yeah. He's already forgotten he was moved and he's settled into his new room as though nothing's changed. He's in a real good mood this morning," she said, eyes twinkling. "Go in and see for yourself!"

I stopped in my tracks and let her statements sink in. "So *I'm* the only one who's still suffering," I said.

"Yes. It's often like that. Residents usually adjust to changes more easily than their loved ones do."

"Ann told me that, too," I said, exhaling forcefully and leaning against the wall. "I guess that may be one of the benefits of dementia. You quickly forget painful things that happen to you," I said, mostly to myself.

Even though he had forgotten about the move, the sound of his voice asking to go home reverberated in my head and troubled me for days.

**October 15:** I visited Ed at 1:00 in the afternoon and found him in the Terrace dining room along with two women and a man. I was not prepared for what I saw. The first thing I noticed was that these people seemed far more demented than Ed and considerably more demented than any residents I'd seen at the Center up to that point. Both women were staring into space. One was repeatedly calling out angrily, "Help me! Help me!" She didn't appear to be speaking to anyone in particular.

The aide on duty, Laura, bent down in front of her and said, "Now, Lucy, you're okay. We won't let anything happen to you."

That calmed Lucy a little, but only for as long as Laura stayed with her.

The other woman, whose name I later learned was Rose, had a pink, grey and white Afghan covering her lap. She was leaning back in her wheelchair, head hanging over on her right shoulder, mouth open, and eyes staring at the ceiling. It was painful to look at her. The man, a vacant stare on his face as well, was being fed by Laura when she wasn't tending to Lucy.

On my way out I passed several other residents, and it seemed they were all more demented than Ed. He seemed to be the healthiest one there, and strangely this made me feel better about the fact that they'd moved him there. Of course I didn't stop to consider that the longer he lived there the more likely he was to become as demented as they. I also took comfort in knowing that he was one of only two ambulatory residents on the unit, but again, I didn't take into consideration that he, too, might well end up in a wheelchair one day.

**October 16:** Ed was weaker than the day before and was walking at the slowest pace I'd ever seen him, stopping periodically to rest and catch his breath. At that rate of decline, I wondered if he'd even be alive in six months. Maybe he did have CHF. I went home and looked up the symptoms on the Internet. He had many of them: shortness of breath, cough, swelling of the feet and ankles, fatigue, weakness, and loss of appetite. The most worrisome thing was that he often had shortness of breath while just sitting in a chair. A dark thought crossed my mind: Maybe I needed to begin discussing end-of-life issues with Dr. Zakem.

**October 17:** Suddenly I felt like an abandoned child. I'd just run into Cindy, the petite brunette Assistant Director of Nursing, and had spoken with her in the little office off the lobby. She agreed with my assessment that Ed might not live more than six months, if that. Even though I was

the one who'd brought it up, I'd been hoping she'd disagree with me. She also told me the tests results had come back and that Ed did in fact have CHF, a startling and undeniable sign that he was becoming more physically debilitated. She told me her opinion as casually as if she were telling me Ed had eaten all his lunch that day. Of course, this was a natural progression of the illness, and an everyday occurrence for her. I wandered around the facility in a fog that day. I thought about stopping to see Ed again before leaving but couldn't bear to see him just after hearing this dreadful news about his health. I felt numb as I walked out to the parking lot. When I got home I e-mailed Marjorie. She answered within an hour, firmly recommending that I check into hospice care. I was startled to see that word on my computer screen.

*Hospice.*

Just the very *word* scared me. I couldn't believe he was declining that fast. He'd just moved to the Terrace five days earlier, for God's sake.

**October 19:** If we were talking about *hospice*, I needed some professional medical guidance so I decided to make an appointment with a physician I knew and trusted – Dr. Doug Smucker, a faculty member at work who specialized in end-of-life care. He was a serious, kind and gentle man. People in the department with loved ones near the end of life often called on him and, being a generous person, he always made time to talk with them.

Thoughts were swirling in my brain, and I struggled to focus as we talked. The discussion was stressful because the sole purpose, as I initially saw it, was to confer with Doug about issues related to Ed's impending death. I had no idea so many complicated issues were involved in dying; and some presented wicked ethical dilemmas for the person making the decisions.

Doug told me that doing CPR on someone Ed's age and physical condition would almost certainly do more harm than good. Risks included broken ribs, collapsed lungs, brain damage, the permanent need for a ventilator, and others. The chance that CPR would even work for someone in Ed's condition was less than 2%. The chance that it would return him to his former quality of life was even less.

From what he said, it seemed decisions about whether to hospitalize Ed and/or put him on a ventilator should be made when needed rather than in advance. The decisions would involve considering Ed's general condition at the time. Was he alert and responsive? Was he in pain?

What was his quality of life? Was he likely to recover from whatever was causing the need for the hospitalization or ventilator? Doug stressed that if an elderly debilitated patient had pneumonia, for example, you could try a ventilator, but if the patient's health worsened, you could then withdraw the ventilator and allow him to die in peace.

He confirmed to me that since Ed was getting out of breath just sitting in a chair, he was eligible for hospice care. However, he said, I could always change my mind and sign him off and on hospice care any time. That was reassuring.

The most difficult question I wanted to ask was one that I didn't *really* want to ask. It was how people died from congestive heart failure if they didn't die from something else first. Doug said that near the end of life the body of a patient with CHF just gradually slowed down, the patient would eat and drink less and sleep more, eventually slipping into a comatose state. Doug's words "eating and drinking less and sleeping more" were burned into my mind as a deadly combination to remember, watch for and fear.

Dr. Zakem had refused to speculate about how much longer Ed might live, so I asked Doug his opinion, and really appreciated that he was willing to discuss it. He said the next couple of months would be telling. If Ed were still alive by the end of the year – it meant by the end of the following month – it was possible he could live another year or so. He said he'd seen people in Ed's physical state live that much longer.

"Marie," Doug said after I'd asked all my questions, yet wasn't at all ready to end the conversation, "the caregiver's *real* question should be 'How do I help this person have the highest possible quality of life during the time he has left?'"

I was unprepared for that question and had to think a moment. Then little by little the answer came to me.

"I guess for Ed," I said, gathering my thoughts as I went along, "that would be by visiting him as often as possible, giving him more stuffed animals and taking little Peter to visit. Those are the things he really loves. Maybe I can think of more later."

"Those sound like excellent ideas," he said.

Doug's advice about 'the real question' had opened my eyes and prompted me to think about Ed's end-of-life situation in a new light, focusing on his remaining life rather than his impending death.

**October 20:** I awakened abruptly in the middle of a nightmare. It was one I'd had many times. Ed had for some unknown reason left Alois and moved back to his Edgecliff apartment. I was terrified, knowing he wouldn't be able to take care of himself for even an hour, let alone all his remaining days, and there was nothing I could do about it.

I looked out my bedroom window and saw it was raining heavily. Dark storm clouds hung low overhead, covering the entire sky and pushing my mood lower than it already was. It was just as gloomy that day as it had been the previous one. I hadn't yet decided about hospice. It did seem like the best course of action, but the very *word* still scared me. I felt signing the papers would be tantamount to signing Ed's death warrant. I knew that wasn't true, but it was how I felt.

**October 21:** She said she thought 'divine intervention' caused our paths to cross. I didn't believe in divine intervention but I was pleased that I met her as I was leaving the Center that day. She was a pleasantly plump young African American girl named Janice who introduced herself as the chaplain from a local hospice service. I guessed she was in her mid 30s. She seemed innocently idealistic and dedicated to her job. I relished the one-on-one attention she gave me. We inconsiderately stood near the main door talking for almost a half hour, forcing visitors to go around us to enter or leave the facility. I told her I was thinking about ordering hospice care for my loved one. When we parted she gave me some literature to take home and read.

**October 22:** I was alarmed. Ed was out of breath during my entire visit and kept falling asleep while sitting in his chair. I needed to tell Rosa, who was planning to visit Ed with me, to come as soon as she could. A part of me was actually afraid he might die before she came to see him.

**October 23:** I consulted with trusted friends, colleagues and professionals about hospice care, and I made the heartbreaking decision to proceed with it. I just had to decide when. I thought Ed didn't need it quite yet, but in my heart I realized that in truth I wasn't ready to sign the papers quite yet.

**October 24:** Marsha, my only remaining friend who was close to Ed *and* who knew us back in the 'good old days,' was visiting from San Francisco. She was the only person who never exclaimed how lucky Ed was to have me. That was because she knew everything *he* had done for *me*. I met her at the airport, where we hugged each other warmly then

drove to First Watch in Hyde Park. During a delicious filling breakfast of blueberry pancakes and crisp bacon, we caught up on each other's lives. Then we went to see Ed. It would be the first time she'd seen him since he moved to Alois.

Unfortunately, he was in the worst state I had *ever* seen him. He was dressed in the pale amber monogrammed shirt that drained the color from his face. It didn't belong to him but the aides thought it did so they kept it in his closet. His eyes were closed, his mouth open and he was half asleep for most of the visit. That had happened before, but usually I could stir him easily. Not that time. When I finally managed to wake him up, he sounded like a ghost. He insisted in a soft raspy tone of voice that Marsha was *not* Marsha, and repeatedly said "I pity whoever thinks this is Marsha." I was so disappointed she couldn't see how sweet and loving he'd become and I worried that this signaled further and faster mental and physical deterioration.

After we left Ed, I showed Marsha around the facility. We ran into Ann and I introduced them. Marsha commented that it was sad to see Ed in that condition, but at least it was comforting to know he was in such good hands. Her voice cracked and she was near tears.

I was reminded of the last time she'd visited Ed when he was still living at the Edgecliff and was only mildly demented. If anyone had told me then that he'd be in such a bad state within a year, I'd have told them they were crazy.

Shortly before that visit, Marsha's father had died unexpectedly. He'd been out shopping with his wife one day. They came home and were in their family room when he had a heart attack sitting right there in his recliner reading the paper. He died before the ambulance reached the hospital.

Marsha was devastated by the loss. It was made worse by the fact she hadn't been able to say good-bye. I could tell that experience had changed Marsha's way of leave-taking when she visited people. I'd noticed that when she said good-bye, she said it as though it might be the last time she'd ever see that person. And so it had been when she'd said good-bye to Ed that day at the Edgecliff. I was touched by how tightly she hugged him, how she talked to him and looked him right in the eye when she said good-bye. And since he was totally confused that day at Alois, her last visit to him at the Edgecliff was in fact the last time she ever saw *him*.

**October 26:** I finally decided to hire the hospice service. Marsha came to offer moral support while I met with the director of the company I'd decided to use, a company many families with loved ones at Alois used. As the man explained their services and policies, he seemed like a low-key salesman, and I guessed that was really what he was. They needed to have enough patients to make a profit. When he finished his understated sales pitch, I signed my name on the many required forms.

All that was taking place behind Ed's back and without his knowledge. As Marsha and I talked with the guy, Ed was sitting down the hall in his room, trying to make sense of Sartre's *Le Sursis*. I found myself wondering how he'd feel about my actions, but then I realized there was no possible way he could grasp their significance to him. I was comforted by the fact that he wasn't aware his death might be imminent. That was one more benefit of being demented. You didn't have the capacity to worry about future events, including your own approaching death.

### **Final Arrangements**

Ordering hospice care for Ed was forcing me to confront the unthinkable: Ed probably had less than six months to live. Since I'm the type of person who plans everything ten steps ahead, I started planning for a small memorial service. I knew Ed could live another year or two, or even more, but I wanted to be prepared. I wanted to 'make his luggages,' to get all of the final arrangement made so I could just relax and enjoy whatever time we had left.

Years before Ed had told me adamantly – and even put it in a notarized statement – that he didn't want a religious service or to "lie in a funeral home." But since he never said anything about not wanting a memorial service, I felt I could have one in good conscience. I planned to have it at the Alois Center, because the only people who really knew him then were those who took care of him, and they'd be more likely to come if it was held there.

First I selected the music. I was going to play a lively movement from Telemann's *Gypsy Sonata* that I had on a CD. When I'd played that piece for Ed years before he'd jumped up from the sofa and started dancing around like a wild Gypsy. He 'r-r-r-really' (as he pronounced it) cut a good figure. No one who knew Ed would have believed the style and vigor with which he'd danced, or even that the deadly serious professor

had danced at all. Then I'd play a selection each by Bach and Handel, composers Ed loved. I'd also ask Jan to play a few patriotic songs to mark Ed's love of this country. Ed really enjoyed her dining room sing-alongs, even if she did play for '*four* hours' each time, as he said.

Then I turned my attention to the eulogy. I reviewed all my e-mails to Marjorie, picking entries here and there to organize into a unified whole. I'd talk about his difficult life in Romania and his life here as a free man before he became demented. I'd also tell touching and humorous stories about his life at Alois. And I'd be sure to include a few of his amusing mistakes in the English language. At the end, since Ed was always kissing everyone's hand, I'd invite people to kiss the hand of the person sitting next to them, "because we know that's what Ed would do if he were here."

The next item was the obituary for the newspaper. I decided to make it pretty short. When I started listing the people he was survived by I got stuck about how to refer to myself. "He's survived by Marie Marley, 'his friend?' 'his former lover?' 'his soul mate?' his 'life partner?'" Finally I settled on 'his companion of thirty years.' That relayed the essence.

Then it was time for the most difficult task of all – pre-arranging the cremation. I didn't know if I could do that alone. It was so macabre. I called Teresa and asked if she'd come down from Dayton and go with me to the funeral home. She said she would, but the morning we were supposed to go she called and said something had come up and she couldn't do it that day. I decided I wanted to get it over with, so I went by myself.

Before he became demented Ed had asked me to arrange his cremation when the time came and told me to use Vielhauer-Clepper on Madison Road in Oakley. After fretting about it all morning I drove there around noon. It was a white building set back from the street with parking lots on both sides. I parked in the one on the left under a big oak tree. I had an immense feeling of dread as I walked to the main door. There was a little hand-printed sign that said to go to the back door if no one answered. I waited a moment in the harsh cold, the wind stinging my downturned face. No one answered, so I went to the back door.

I knocked and waited as I pictured Ed sitting in the dining room at Alois calmly eating his lunch, unaware that I was carrying out the dreadful task he'd assigned me all those years ago. There was still no answer and I knew I was going to be really annoyed if I gotten up all the



courage to do this and no one was there. I knocked again, with more force. Soon a balding middle-aged guy with a modestly protruding belly appeared, wearing a black suit and maroon and gray striped tie over a crisp white shirt.

*Must have had a service today.*

He was even wearing wing tipped shoes.

Mr. Clepper, as he introduced himself, motioned for me to follow him. We went down an incredibly steep and narrow carpeted stairway, and entered a huge office. He pointed to a chair for me, then sat down at his desk, his chair creaking as he leaned back.

After some initial small talk, he told me an amusing story about a previous client. I got the feeling he was lonely in his job. Shortly after that I summoned the courage to tell him the reason for my visit.

"I'm here to make prearrangements for the cremation of my life partner of thirty years."

*As if he needed to know the details of our relationship.*

He asked me several questions and filled out a form as we talked. After he finished with the form, he pointed to the large selection of urns on display and asked me to select one. I hadn't thought about that and wasn't prepared for it. It just made it all that more gruesome. I told him I couldn't make up my mind on the spot, so I paid for one but left the decision as to the exact one until later.

When everything was finished he walked me to the parking lot where he told me an amusing story about still another client. I stretched out my leave-taking, encouraging him to tell me more stories - not because they were so interesting but because I realized that the next time I saw him would be in Ed's room at Alois.

### **Sudden Death**

It was late evening and I had just finished packing to go visit Marsha in San Francisco the following day when the phone rang. It was a man I didn't know. It was a man who introduced himself as Dr. Ashburg.

"The situation is grave, Ms. Marley. I'm sorry to have to tell you this, but you should come immediately."

"Oh! my God!" I answered, suddenly feeling weak. "What *happened?*"

"Stroke. And it's a bad one. We're doing everything we can, but frankly I don't have a lot of hope."

*This can't be happening. Everything was fine yesterday.*

I'll be there as soon as I possibly can," I said, pushing Peter off my lap and standing up.

We finished talking and I hung up, feeling light-headed. Considering how serious he said it was, I wasn't sure I could make it in time. I hurriedly called Delta, my hands shaking and my heart beating rapidly. I changed my ticket from San Francisco to Ft. Worth. Mother was dying.

Despite our mutual contempt for each other, I stayed at my brother's house. Phillip and I had always resented each other because my father encouraged us to rat each other out and so we did, sometimes even lying to get the other in trouble. The punishments we received were viciously brutal, and we never forgave each other, despite both having tried.

Phillip's wife, Diane, a woman I'd never spend time with if she wasn't 'family,' was kind enough to pick me up at the airport. She drove me through the crazy Dallas-Ft. Worth traffic directly to the hospital, where Phillip was sitting in the Intensive Care Unit's waiting room. He said he'd already seen mother that day and didn't need to see her again. Diane, who didn't much care for my mother and didn't try to hide it, said she didn't need to see her either, and so I went in by myself.

When I first entered, mother was breathing heavily and her eyes were staring at the ceiling. I became light-headed and my hands were unsteady. As Phillip and Diane had forewarned me, she was unable to talk. When I held her hand, however, her eyes shifted and locked onto mine. I told her repeatedly that I loved her. She looked at me with such intensity that I felt she was trying to tell me something – probably that she loved me, too.

I cherished my mother more than life itself, and I knew from the doctor it was just a matter of time until this sweet, innocent, loving soul who had suffered so much in her life would be gone forever. I couldn't imagine that my grief would ever end. After twenty minutes of repeating my mantra to her, I returned to the waiting area where my difficult relatives were sitting; Phillip staring at the wall, Diane watching TV and cracking her gum.

We went to a Mexican restaurant where we did our best to be civil with each other. Immediately afterward they took me back to the hospital. I spent another twenty minutes telling my mother how deeply I loved her.

The call came at 4:00 AM.

While Diane was at work, Phillip and I made the arrangements, which reminded me so painfully of making Ed's arrangements. Before bedtime I wrote the eulogy.

*How many eulogies should a person have to write in one week?*

Though I almost never cried, I burst into tears repeatedly in the following days. Somehow I got through the funeral and burial, at times thinking about Ed's impending death. I'd lost Ed to dementia. Then mother died. In the not too distant future Ed would die, too. All the losses were mixed together in my mind, and I couldn't disentangle them. My heart was filled with pain; my grief engulfed me.

As the plane took off back to Cincinnati memories of my *father's* death and funeral, eight years earlier, flooded my mind. The phone had rung early one Saturday morning. It was Diane.

"Your dad died this morning," she said in her typical blunt, unemotional way.

I was shocked.

"What did he die of?"

"He just died," she said blandly.

They say it's common for people who were abused as children to feel like they deserved the abuse. That was true for me. I recall sitting at the funeral listening to *Amazing Grace* being played over the chapel's speakers and saying in my head over and over to my father, "I'm sorry I was such a difficult child." I tried to cry but found I couldn't. I felt guilty for not crying when so many other people there were in tears. My father's death didn't make me cry but it raised a plethora of unresolved issues that tortured me for months after his death.

Trying to put those thoughts out of my mind, I got out my laptop, and for the rest of the flight home I attempted to work on a grant that was due right after my return. Needless to say, I got nothing done and it was a miracle that I didn't miss my deadline.

### **Wearing Black**

The next day I went to see Ed. It was a sunny but bitterly cold day. The temperature had been so low the previous night the car was freezing even though it had been in the garage. The steering wheel chilled my hands and I couldn't banish the morbid vision of my mother's cold body lying in her grave.

I was so grief stricken when I arrived I didn't really feel like seeing a bunch of elderly people whose deaths were not all that far away. I entered anyway, of course, and found myself looking at the residents in a strangely different way. My attention was first drawn to Carol with her teddy bear, and her petite brunette daughter, Phyllis, who was visiting just as she did every Sunday. I thought it was sad that Carol always carried that teddy bear, but I guessed people probably thought it was sad that Ed loved his stuffed animals so much when, in fact, they brought him great joy.

For a moment I found myself staring at Carol, wondering how much longer she might live. Then as I crossed the lobby I saw Mr. Brooker wearing his familiar forest-green sweater, making his daily visit to Denise. I started wondering how long she might live. Then my mind spontaneously turned to the gruesome question of Ed's remaining time.

As I continued toward his room I realized I wasn't looking forward to seeing him because I didn't think he'd understand when I told him my mother died. And I certainly didn't expect him to be able to comfort me, as he would have even a year before. I prepared myself for the absence of empathy. He was sitting in the rocking chair dozing, so I called his name. It surprised him and his head bobbed up. Then an instant later he recognized me, and a smile came to his face.

"Oh! Kitty! It's you. I'm so happy to see you."

I was glad to see him so lively. I hadn't seen him since Marsha was there, when he'd been in such a pitiful physical and mental condition.

I sat down in the rocker and stupidly asked him, "What did you have for lunch today?"

*When am I going to remember he doesn't know if he had lunch, let alone what it was?*

"I didn't have lunch today," he said definitively.

I decided to let it go and relate an interesting news event before telling him about mother.

"Kitty," I said. "Guess what? Saddam Hussein was just convicted of crimes against humanity and sentenced to death by hanging."

Ed had followed the news all his life. He'd read the newspaper every day and he'd watched all the news and political commentary shows religiously. He hadn't missed a single day of the Watergate hearings, the OJ trial, the Clinton impeachment hearings, the coverage of the Bush-Gore election dispute, the several days-long Reagan funeral, or any of

the other major events that were broadcast on TV. So even though on an intellectual level I knew he no longer kept up with what was going on in the world, I wasn't emotionally prepared to hear his response.

"Who is Saddam Rustay and what crimes did he commit?"

I was enormously saddened by this and decided to just change the subject and tell him about my mother. I was certain he wouldn't remember her, even though they'd met several times over the years and had liked each other. Like me, she'd been especially attracted to his distinctly European manners.

"Kitty," I began, feeling sad just thinking about it. "My mother died last week. You remember her? You met her a few times."

He looked up from Adorable, whom he was 'padding.'

"Honestly," he said after a few seconds, "I don't remember her, but I'm very sorry she died."

I gave him a prayer card bearing her photo. He turned it over and saw the praying hands on the back and thanked me several times. I also gave him the eulogy I wrote. He studied it for a long time. Since his ability to read was very limited I wasn't sure how much of it he could understand, if any thing at all.

"This is very beautiful, Kitty," he whispered. "You should be proud of yourself for writing such a lovely thing."

Then he read the last sentence out loud perfectly.

"In closing, Flora often said 'I've had a good life, and when I'm gone I don't want you kids to cry.' To that we kids say, 'Sorry, mom, we tried to honor your request, but just can't do it.'"

"Just can't do it," Ed repeated, the paper quivering in his hand. He looked up at me and said it once more. "Just can't do it."

Then he put the prayer card and eulogy on his night stand.

When I left I said, "I'll come back again tomorrow."

"Oh, I am very happy to hear that," he said.

I had been a little worried that perhaps telling him about mother's death might make him think about his own death, but then I realized he didn't have the capacity to make such links any more.

"Kitty, you remember I told you my mother died?" I mentioned the next day.

"My mother didn't die," he said, looking baffled. "I just talked to her last night."

"No, Ed," I said. "I'm talking about *my* mother. My mother died – not yours."

"My mother is fine," he said, still confused.

I dropped it.

Three days later, casually dressed in black jeans and a black cotton turtleneck, I was sitting with Ed as he ate his lunch of unappetizing pureed something or other and tapioca pudding. I was so distraught over mother's death I'd decided to wear a black blouse or shirt every day for a month.

When he finished eating he put down his spoon, looked directly in my eyes, and said, "You look so beautiful in that black shirt even though I know you're wearing it for death."

I was stunned.

### **Filling the Void – Again**

The first Saturday since mother died, the first Saturday I couldn't call her, the pain was blazing. Every time I glanced at my phone it was a stinging reminder that she was gone. The hours passed at a snail's pace after I returned from visiting Ed. I felt lost.

*I can't call. I won't be able to call tomorrow. I won't ever be able to call again.*

Each time I passed my phone, the pain was stronger than the time before. I realized I had to do something. I needed to have a regular connection with a living soul. But with whom could I talk on the phone as much as I did with mother? I reviewed my list of friends – as I'd done before – and came up empty handed again. None would want to talk so long three or four times a week.

After much thought I realized that the only person I could expect to become my new 'phone companion' would be Freddie. She was the only person left I thought would be willing to spend so much time on the phone, even though we really had nothing in common to talk about.

When we were kids, Freddie was always the fragile one, and she'd remained so throughout her life. While Phillip and I were often belligerent toward dad, and the consequences were dire, Freddie would cower in the corner and try, usually successfully, to avoid getting into trouble. I always felt sorry for her, took her under my wing, and tried to protect her.

When she got older she told me privately that dad had molested her when she was a child and she hated him for it. She said she had

nightmares about it all the time and that it was a 'recovered memory,' a theoretical psychological phenomenon that was very popular at the time. It seemed like every week you heard women discuss their 'recovered memories' of sexual abuse on Oprah or some other afternoon TV show. I'd always doubted that dad molested Freddie. I certainly didn't have any 'recovered memories' of any such thing happening to me.

During her 20s and 30s she went through a string of men I'd describe as losers, most of whom she'd met in bars. She only had a high school diploma and thus couldn't really find any high-paying jobs. She lived in abject poverty. At the time mother died, she was 50 and still living in poverty. She was married to a man who was on Social Security Disability and took an incredible amount of medication, including narcotic pain killers he needed due to a severe neck injury he'd sustained during a fight at work. Because of the substantial amount of sedating medication he took, he slept most of the day.

I knew I could never replace my calls to mother. But in desperation and loneliness, I decided to try fill the void at least a little by calling Freddie more often. I knew she was feeling the same painful vacuum. And so it was that we began our talking ritual. I called every Wednesday, Saturday and Sunday – the same days and times I'd called mother. Freddie didn't comment, but I thought she understood why I'd started calling her so often. Previously we'd only talked about once a month, if that.

While mother and I'd had little in common, Freddie and I had really no mutual interests. In the beginning our conversations were formal and uncomfortable, filled with many awkward silences. We talked mostly about what was going on in our respective lives. But our worlds were so far apart we each had to struggle to relate to the other. Yet just as had happened with mother, after awhile we came to enjoy our talks. They provided an emotional comfort and structure that helped us both continue our lives after mother's death.

Ed was demented and mother was gone, but life continued despite it all.

## Chapter 12: Precious Moments (2006)

### **Please Wear a Tux**

“Please wear a tux,” I said over the phone to the classical violinist I was hiring to play a special concert for Ed. My dear friend, Teresa, had hatched the idea. She’d called CCM and found a violinist, Don Hurd, who did freelance work. As I was talking to Don to make the arrangements, I described Ed’s dementia, adding that he had been a college professor who loved classical ‘moo-sic.’

I was nervous about the whole plan, worrying that Ed might be in a bad mood and tell Don to leave. He still had an occasional temper outburst. That was always on my mind whenever I was inviting people to visit Ed. After fretting about it, I decided to take the chance and go ahead despite my reservations. The concert would either bring Ed great joy or be a total disaster. That was just the way it was when you were dealing with a demented person.

I arrived early so I could be sure Ed was shaved and dressed. In the hallway I ran into the hospice nurse, Ruby, just leaving after her weekly visit with Ed. She was around 5’ 8” and weighed about 120. So her physique was just about identical to Ed’s. She wore very thick glasses and her exceedingly thin face made me think of a sweet little bird. And she was sweet. One of the sweetest people I ever met.

“How is he today, Ruby?” I asked expectantly.

“He was asleep sitting on the sofa when I got here, but I woke him up and we had a great visit. I let him explore all the compartments in my briefcase like you suggested. I have to admit I was surprised. He *loved* it, just like you said he would.”

I laughed. I’d told her at our initial meeting that few things made Ed happier than exploring pockets and compartments in suitcases, briefcases or even purses. She’d looked at me like I was a little crazy.



“By the way, I’m going to call the Romance Languages Department at UC and see if I can get a student volunteer to come out and talk with him in French,” she told me.

“That sounds great,” I said.

“Well, I’ve got to run. I have another resident to see over in the Gardens.”

*The Gardens. The place they go to die.*

When I arrived at Ed’s room I was relieved to see Janelle had him shaved and nicely dressed in a light blue shirt and his grey tweed sport coat, the one with leather patches on the elbows. Believe it or not, it was the same sport coat he was wearing the day Guido introduced us way back in 1975.

While we waited for Don, I sat on the sofa with Ed. We talked about the conversation he’d had with his father the previous evening. Of course he hadn’t had any such conversation, but at this stage of his illness, I’d always try to connect with him in whatever time period he seemed to live. I glanced at my watch, which told me Don was late, and I wondered if he’d gotten lost or delayed in traffic. After ten minutes or so I went to the lobby to see if maybe he was waiting for me there.

What I saw amazed me. Don was there alright, his tuxedo making his svelte physique appear even slimmer. His round face, pale blue eyes and thinning blond hair stood out against the black tux. He was standing in the middle of the huge lobby, violin tucked under his chin, playing Brahms’ *Lullaby*. Carol stood a few feet away, wearing the same off-white sweater she’d been wearing every time I’d seen her, her teddy bear cradled in her arms. I greeted Don and he shushed me. “Don’t wake the teddy bear,” he whispered, sounding serious but with a twinkle in his eyes. Carol looked radiant. I could tell Don had an amazing aptitude for entertaining dementia patients. Maria, wearing a burgundy pants suit with a pink frilly blouse that flattered her olive complexion, was observing all this from her receptionist desk. She winked at me and I smiled back.

When the lullaby was finished, I introduced myself to Don. Then we walked toward Ed’s room, passing numerous open doors. Most of the residents were up and about, but we saw a few in their rooms. Doris was watching her huge flat-screen TV with the sound turned off, futilely cupping her left hand to her ear. Edna was talking with her son, Jerry, who was dressed in jeans that had holes in them and a tee shirt that was

none too clean. Tony was dozing, leaning over, one arm draped over the arm of his chair and nearly touching the floor. Teresa, one of the marvelous Terrace aides, was animatedly pointing out a squirrel on the oak tree outside Harry's window, while helping him put on his shoes.

Just before we reached Ed's room we ran into Rhonda, my favorite Terrace nurse. She did a double take when she saw Don in the tux. "Way cool!" she exclaimed once I had explained why he was there, and continued down the hall with her medication cart. We were finally at Ed's door and I was about to learn how he was going to receive Don. Our entrance startled him and he jerked to attention. I introduced Don and told Ed he was going to play a special violin concert for him.

"Oh! Superb! Wonderful! I'm honored!" Ed said as he shook Don's hand.

I had the feeling Ed was really impressed by the tux.

So Ed was honored and I was relieved. I set up my tripod and fastened my camera to it. I planned to take many pictures, hoping to get at least a few good shots of what I hoped was going to be a special occasion. The longer Ed was at Alois, the more I felt photographs would be important to me later. I kept a tripod in my trunk and almost always brought along my little Sony Cybershot.

Don sat down on the tan metal folding chair I'd placed in front of Ed. He scooted the chair even closer, only about three feet from Ed, and began playing a Strauss waltz. The sounds were lively and luscious. I watched as his bow flew up and down, his fingers danced around, and his head snapped back on the high notes. Ed looked captivated. His eyes glued to Don, he had a rapt expression on his face and moved in time with the music.

"Bravo! Bravo!" he boomed in his bass voice while clapping at the end of the waltz. "That was the most beautiful 'moo-sic' I have heard *ever* in my entire, very long, and I emphasize *very long* life."

Don thanked him and began playing a Romanian piece, as I'd previously requested. It was one of Enesco's rhapsodies. Ed smiled broadly but I couldn't tell if he realized it was music from his Romanian homeland.

"Bravo! Bravo!" he called out again, clapping like before. "That was the most beautiful 'moo-sic' I've heard," he said. "Ever," he added. "I don't have words to say how happy I am that you are playing *just for me*."

"Thanks," Don said. "I'm glad you liked it."

"My father played the violin," Ed said, "but not nearly as well as you."

Ed reached his hand toward Don and Don grasped and held it.

"What did you teach when you were a professor?" Don asked.

"I don't r-r-remember," Ed answered. Then he added, "Honestly, I'm not even sure I was a professor."

I interrupted their little talk and since there were so many Gypsies in Romania and that was part of Ed's culture, I asked Don to play some Gypsy music. He played Bizet's Habañera from Carmen, and Ed sang along, jabbing his index finger in the air in time with the music.

"Tra la la-la, la la la la-la," he sang, a twinkle in his eyes.

"Bravo! Bravo!" he shouted when Don finished. "That was the most beautiful 'moo-sic' I have heard ever in my entire very long, and I emphasize *very long* life," he said for the third time. "You are the most talented 'moo-si-cian' I have ever heard, and I r-r-really mean it from my heart – it's not just words from my lips."

Don played half an hour longer, the music interspersed with more hand holding and small talk. When the concert was finished, I asked Don to sit on the sofa beside Ed so I could take a picture of them. Ed put his hand on Don's arm and I snapped the photo. After that Don tried to rise to leave but he had trouble because Ed wouldn't turn loose of his arm. Finally Don extricated himself.

"When are you coming back?" Ed asked.

Since Don didn't know to say "tomorrow," I jumped in.

"He's coming back tomorrow," I said, turning toward Don, hoping he'd get the message.

"Oh! How wonderful! I'll be here waiting for you."

Don left after many more good-byes, more excited compliments from Ed and thanks from me. I felt elated that the concert had brought Ed so much joy.

Some of the photographs were adorable. They captured the happiness of a man who had lost so much, yet was still capable of great joy. He was a man who wouldn't remember the concert the following day, but he thoroughly enjoyed every second of it as it happened. In the pictures Ed looked as happy as I'd ever seen him. One of them shows him with both arms outstretched toward Don as he was playing. Another, taken when they were sitting on the sofa, shows Ed with his hand on Don's

arm, looking as proud as if he were sitting next to the President or the Queen of England or something.

The concert was such a success I planned to have Don return sometime. Unfortunately, I waited too long.

### **New Beginnings**

I didn't know it then but the conversation I was about to have with Dr. Warshaw was the first in a long series of events that would eventually transform *every aspect* of my life in the most miraculous ways. Gregg, who'd recommended the geropsychiatrist to me, was one of the most pleasant professors I'd ever worked with in my job at the Family Medicine Department. We'd struggled through the preparation of many successful grants over the years, so when he stopped by my office that day I just assumed it was about a new grant on which he wanted me to collaborate.

Turned out it was a new grant alright, but not for UC. He was working with the American Academy of Family Physicians, the national association for family doctors, in Kansas City, to put together a one-year \$500,000 planning grant to The Atlantic Philanthropies (Atlantic always made a big deal about – capitalizing the 'T' in 'The'). Atlantic was an international foundation that had expressed an interest in funding some of the Academy's continuing medical education programs in geriatrics. If the planning grant activities were successful, then the foundation would consider a much larger grant, something around three million over three years.

But the Academy had a problem. And it was a big one. While they were expert at obtaining grants from pharmaceutical companies, they didn't have anyone on staff they felt was capable of writing such an ambitious foundation grant. Gregg told them *he* knew someone who could do it, and that the person just happened to have an office right down the hall from his. So to make a long story short, the Academy ended up hiring me as a freelancer to write the grant.

The project took up an unusually huge amount of my time and it was during this period that I stopped visiting Ed on weekdays and began going just on weekends. And even after the grant was finished I continued visiting just on weekends. I decided it was time to begin spending some of my free time on myself. Initially I had no earthly idea what else to occupy myself with, so I sat down and made a plan. I

decided I'd go visit Marsha and Teresa more often. I also planned to have them come see me more often. And I decided to spend more time with Irene, Barb, and my other friends from work. I thought about getting a puppy, but decided that might be too stressful. House training Peter had nearly driven me crazy. So wisely, I thought, I'd put that off until later. Much later.

And since I no longer had the stress of single-handedly taking care of Ed, I thought I'd have the required peace of mind to finally do something about my weight. I needed to lose a good 65 pounds, and so I went to see my internist, Dr. Lafranconi, to discuss the issue. We had a long talk about my eating problems and put together a detailed and carefully-thought-out eating and exercise plan, which I followed religiously. That's how I'd always been. Once I made up my mind to do something I stuck to it tenaciously and persevered until I reached my goal. It took me eight months, but I ultimately lost all the weight and ended up looking and feeling like a new person. Ed, however, was too far gone to notice. He'd been after me for years to lose weight. Had he not been demented he'd have been *so* pleased.

Writing the Atlantic Philanthropies grant was just the beginning. A few months later I learned that Sandy Panther, the Academy's Vice President for Development, the woman who'd hired me to write the grant, was coming to Cincinnati on business. For some reason I've never understood, I decided I wanted to meet her. I was by nature very shy, and normally wouldn't have wanted to meet someone in such a high position.

On a rainy Monday morning we met for breakfast at the Kingsgate Marriott on the UC Campus. During the course of the conversation she mentioned that they were planning to hire someone to write grants to foundations – another of my specialties. I had no interest in this position because there was no way I'd leave Ed and go to Kansas, and he was far too frail to move with me. But a little later she told me that given the nature of the job, the person could telecommute. Well, that changed everything.

That job would solve all my career problems. Congress had recently cut the money designated for family medicine grants and thus my job was in serious jeopardy. My department wasn't capable of successfully competing for large national foundation grants, so there was really no way I could get *any* large grants for the department – just small local

foundation grants. *The writing was on the wall.* I knew that in a year or two they'd have to let me go.

I spent the rest of the breakfast elaborating on my stellar grant writing record, hoping I was being subtle about it. On and off throughout that day and many days to follow, I thought about the job at the Academy. It was just a tiny thought in the back of my mind. It didn't occur to me that I might actually *get* the job.

### **You're Always in My Heart**

One morning I hoped to cross off yet another critical item on my long 'preparing for the end' list. Rosa was coming to visit Ed. I'd asked her to visit so she could experience first hand how sweet, loving and joyful he'd become. Since she was my therapist and would one day be helping me with my grieving, it was especially important to me that she visit him. In recent years she'd mostly heard about his verbal abuse, and although I'd told her how dramatically he'd changed, I wanted her to see him and interact with him *in person*. When the time came I simply wanted her to understand what I'd lost.

It was a cold November day and I rushed into the building to escape the bitter wind that was blowing leaves in wild circles around the parking lot; they looked like tiny leaf tornados. The usual 'lobby residents' were carrying out their usual 'lobby activities.' Carol and Edna, dressed like twins that day – both wearing print dresses – were drowsing, their heads resting heavily on their chests. Edna's mouth was open and she was dribbling ever so slightly onto her bib. Carol was so limp I feared she was in danger of dropping her bear. Albert, dressed in his grey sweats, with the left pant leg pushed halfway to his knee as always, was pacing the floor, pushing his walker in front of him. He paused at the front desk, probably asking Maria the same question he always asked: "Where is my house?" Joyce, her large pink sweats dwarfing her thin frame, stood alone at the baby grand, staring into space through her thick lenses. She was putting her weight on her left foot, as though she were about to take a step forward with her right. "What am I supposed to do?" she asked of no one in particular. Alice, noting Joyce's discomfort, walked over and took her by the arm. "Let's go sit on the sofa, Joyce, and listen to the radio."

I looked for Ed. When I didn't see him I figured he was in his room.

As I headed toward the Terrace I was concerned about Ed's mood, my constant worry when he was going to have company. I'd debated with myself about having the visit with Rosa – just as I'd debated about having Don come and play.

I was an hour early because I wanted to make sure Ed was awake and dressed. I pressed 4421 on the key pad and entered the Terrace hallway. The first person I saw was Janelle. I was delighted she was on duty that morning.

"Hi, Janelle," I said as the door automatically shut behind me. "How's our Mr. Ed today?"

"Today he's feeling great, but I have to tell you he's been weaker lately and he's been sleeping more and more during the daytime," she said.

*That's what Dr. Smucker said happened to CHF patients near the end.*

I dismissed that thought immediately.

"Ed's going to have a special visitor this morning."

"Oh! Wonderful! He loves company. I'll get him all fixed up like a gentleman. He *is* a gentleman, you know? That's what he is, alright. A gentleman. He should look like one, too."

We stepped into Ed's room. I looked out and saw two sparrows at the bird feeder outside his window, pecking away at the birdseed, then flying off only to return a few seconds later and start pecking all over again. Ed was sitting on the sofa, wearing his old threadbare blue cotton pajamas. *I really have to get him some new pajamas.* His hair was disheveled, his feet were shoeless, and a day's worth of stubble was on his face. He almost looked like a homeless man, but I knew Janelle would change that quickly. I greeted him and he exclaimed how happy he was to see me, adding that I was "*so beautiful.*" He seemed alert and in a good mood.

I sat down in the comfortable rocking chair that beckoned me with its thick tie-on seat and back pads, and scanned the newspaper while I waited. Ed and Janelle chattered away while they walked into the bathroom and began the transformation, showering him, shaving him and slicking down his hair. I wouldn't have put that greasy stuff on his hair, but she was the aide, not I.

She dressed him in a white shirt and his chocolate brown corduroy sport coat. He thanked her abundantly as they came back into the room. He *did* look like a gentleman. No one would have guessed that this handsomely-dressed man had removed all his clothes in the dining room

the day before. They told me Sylvia's screams had been audible all the way out to the lobby.

"A good friend of mine is coming to visit you today, Kitty."

"Oh! I'm delighted!" he said. "Is she your mother?"

"No, she's a good friend. Her name is Rosa," I said.

There was no point in explaining that she was my therapist.

"Oh! Rosa!" he said. "That's a lovely name. Is she your mother?"

"No, Kitty," I patiently answered him again. "Rosa is my friend."

As if on cue, Rosa burst into the room. Wearing casual black slacks and a brilliant magenta blouse that matched her vibrant energy, her presence filled the room with an air of excitement. She had dark hair, even darker eyes, and constantly gestured with her hands as she talked, making it easy to guess she was part Italian. Emotional by nature – and culture – the visit was special for her. She genuinely cared about me and wanted to connect with Ed at the deepest level possible, given what his mental status might be that day.

After I introduced them, Rosa sat on the sofa beside Ed. They took off having a lively discussion, Rosa gesturing and Ed motioning with his shaking hands. It was as though they were lifelong friends who hadn't seen each other for awhile. I was amazed. Ed was pretty lucid, except for his confusion about whether Rosa was my mother. I realized it was going to be one of those precious times when, for some mysterious reason, he regained his faculties, if only briefly. While those rare occurrences made me happy, I often plunged into sadness as well because they were but temporary, fleeting glimpses of his past; a past I still longed for.

I watched them. Ignoring me completely, as though I were an inanimate extension of my chair, they suddenly stopped talking, held hands and looked at one another. They didn't utter a word. They just held hands and gazed into each other's eyes. Ed finally spoke. Like a child, he simply said what he was feeling.

"I'm looking at your face. . . I *like* it. You are *so* beautiful."

"I'm honored to visit you," she told him.

"Huh! I'm *twenty* times honored to see you."

*How can a demented man make such a spontaneous and beautiful response to a total stranger?*

Rosa moved to a folding chair and we arranged ourselves in a little circle, she in her chair, Ed on the sofa, and I in the rocker, which I'd



moved over near them. We listened to a Tony Bennett song on a CD Rosa brought. It was about two lovers who later became inseparable friends and cherished each other until the last days of their lives. As we listened, Rosa teared up.

"It gives her tears," Ed said, pointing to her face.

As the music continued, we all held hands. At the end, Rosa fished her wallet out of her oversized purse and showed Ed pictures of her grandchildren. Then she related a recent talk she'd had with her granddaughter, Jennifer.

"I told Jennifer," she said, pointing to Jennifer in the photo, "that when you love someone they are always in your heart and you are always in their heart, even if something happens to one of you."

She turned to Ed and said slowly and loudly, emphasizing each word.

"You're always in *Marie's* heart and she's always in *yours*."

"Ma-r-r-rie's always in my heart. . . but I'm not sure I'm always in hers," he said.

"Yes, Kitty. You're always in my heart," I assured him, patting him on the shoulder.

"Oh. I'm very happy to hear that."

Feelings were simple for Ed. His mind didn't delve into the mixed feelings we can have. The lingering doubts. Suspicion about other people's motives. I told him he was always in my heart and that settled it for him.

We talked for another five minutes, then Rosa left after numerous good-byes, thanks from Ed ("from the bottom of my heart"), and hand kisses. I lingered. Ed said Rosa was a marvelous lady and asked if she was my mother. I told him she was a friend. Then I had to leave as well.

"When are you coming back?"

"Tomorrow."

"Wonderful! Marvelous!"

Ed was in many ways a typical dementia patient, experiencing periods of lucidity interspersed among long stretches of dementia. Yet at the same time, he had always been inimitably eccentric, and his dementia hadn't changed that.

Whenever Ed wanted his way he shouted, "I'm in America! I can do (or have or say) anything I want!" He used that phrase when he wanted the facility to turn the parlor lights brighter rather than lower in the late evenings, when he wanted to eat in the middle of the night, when he

wanted to be served Stouffer's frozen dinners, and, of course, early on when he wanted his vodka.

And he turned the phrase around to avoid doing anything he didn't want to do. He would say things like, "I don't have to get out of bed today. I'm in America!" Or he would declare, "This is America! I don't have to get a haircut!" He sometimes firmly stated, "I'm an American! I don't have to get dressed today." Above all, he was happy to be in America because he thought the American government was paying his bill for the Alois Center. I just let him continue thinking that.

Ed had always had a horrible appetite and was underweight all his life. The Alois aides were constantly trying to get him to eat more. When an aide once told him I was concerned he wasn't eating enough he said, "Eef Ma-r-r-rie's worried that I'm not eating enough you have her come here and tell me that herself!" Another time when an aide was urging him to eat, he finally smiled impishly and said, "*I'll eat it if you eat it!*"

In many cases, Alzheimer's patients become grumpy or even downright mean as their dementia advances. As Ed's progressed, however, he went the opposite way and many of his sweet and loving qualities from our early years together became *more* pronounced. That wasn't to say he never got angry – because he did – but overall he became a sweet, adorable and joyous man, especially after he started taking the psychotropic medicines. He became even *more* of a gentleman than before, always telling his guests and the staff (male and female) how beautiful they were. He even said it to those who were rather unattractive. They were all beautiful *in his eyes*. If only we could all see beauty everywhere we look.

As I walked back up the hall, through the lobby, and into the crowded parking lot after the lovely visit with Rosa, I tried very hard not to think about what Janelle had said when I'd first arrived that day - that Ed was eating and drinking less and sleeping more. Yes, I tried not to think about that.

### **'Conducting' a Visit**

A strikingly handsome young man was signing out as I entered the Center with Peter the next day. His general demeanor led me to believe he was a successful young professional. He had jet-black hair, dark brown eyes, and a strong jaw.

"What kind of dog is that?" he asked, smiling at Peter more than at me.

"He's a Shih Tzu," I answered. "His name is Peter."

"I'm Tom Brooker," he said, extending his hand.

"Oh. You must be here to visit your mother."

"Yes, I am. And you know what? My mother loves dogs. Would you do me a favor? Could you take Peter to see her? She's in the Terrace. Her name is Denise."

"Sure," I said. "I'll stop on my way to visit my friend."

I entered the Terrace, found Denise's room, and peeked in, finding a woman with short, straight grey hair lying in bed and wearing a thin, off-white nightgown. Her eyes were half closed, but she seemed to be awake.

"Mrs. Brooker," I called out in a soft voice. "Are you awake?"

She opened her eyes fully and nodded 'yes.'

"Hi," I said. "I'm Marie and I just saw your son in the lobby. He asked me to bring my dog to see you. His name is Peter."

"Oh! Wonderful! I love dogs."

Since she didn't sit up or anything I picked up Peter and held him near her. Peter immediately licked her face. She laughed and petted Peter.

"Gee, I'm surprised," I said. "He doesn't usually kiss people he doesn't know."

"Dogs are very selective," she answered, her lucidity astounding me.

After a few moments I told her I had to go visit a friend, but would bring Peter back another time. She thanked me and I headed toward Ed's room. I vowed to stop by Mrs. Brooker's room again soon, and whenever I did, Peter always seemed to bring her joy.

Ever since Ed entered the Alois Center people suggested that I listen to CDs with him, but I hadn't because I thought it would be boring for me and I didn't think he would really enjoy it either. Nonetheless, that day I decided I'd try it.

When I walked into his room he was sitting in the rocking chair sound asleep, his body perilously leaning over to the right. His mouth was partially open and he was snoring. I called out his name, which usually awakened him but that day it didn't. So I went over and gently shook his shoulder. That did the trick. He woke up and looked at me as though I were an angel. A big smile appeared on his face and he told me how beautiful I was. After we talked awhile I put on a CD of Mozart's

Jupiter Symphony and started it at the last movement. His eyes sparkled, his whole face beamed, he sat up straight, and moved in time with the music. It was a joy to see him come to life like that.

Then, for some reason I can't explain, I began 'conducting' the music. That made him *really* smile. As I was 'conducting,' I recalled that years before he'd always enjoyed watching conductors on TV, especially the flamboyant ones. The wilder they were, the more he loved watching them. So I decided to emulate that type of conductor. I conducted with both hands, arms flying around, sometimes in tandem, other times going in opposite directions. I pretended I had a baton in my right hand, cueing each section of the orchestra when it was time for their entrances. My background in music helped me pull off the whole charade in a convincing and entirely accurate manner – not that Ed would have known the difference.

I stretched out both arms and bounced up and down on the balls of my feet when the music was loud, then crouched down and conducted in a tiny circumscribed area using only my right hand when the music was soft. When the music was the *most* pianissimo, I put my left index finger up to my lips in a "shh . . ." gesture while my right hand continued conducting in small circles.

I constantly shifted my gaze to the section of the orchestra that was playing the most prominent role at a given moment – violas and basses on the right, first and second violins on the left, cellos in the middle, woodwinds and brass in their respective places behind the strings. After the final chord I made a gigantic cut off movement, paused for a few seconds, then bowed deeply – first to the right, then center, then left.

Ed, who had been sitting in the rocking chair during the entire theatrical production, looked positively radiant. After my final bow he looked at me and said in an almost reverent tone of voice, "What you did was *so* beautiful."

How wrong I'd been. Listening to CDs with Ed was anything but boring.

### **A Lesson for Caregivers**

"Oh! No, Kitty! I take them every day with no r-r-remorse." I told Pat and Freddie that's what Ed always proudly announced when I told him not to steal the dining room table spoons.

Pat, Freddie and I laughed at Ed's idiosyncrasy.

“But no matter what I say,” I continued, “after eating, Ed carefully cleans his spoon with a napkin, then wraps it in another napkin and puts it in the breast pocket of his sport coat and takes it to his room.”

“How funny!” Freddie giggled.

It was a pleasantly warm winter afternoon and I was visiting Ed with my sister Freddie and our cousin Pat, who had never met Ed before. Pat was the third of six children of our Aunt Alice. On our way to Alois, Freddie kept applauding my sixty-five pound weight loss. It was the first time she’d seen me since I’d lost the weight and she could hardly believe it. She brought it up so many times I was a little embarrassed.

We arrived and signed in at the front desk. Maria was on duty. She immediately commented that Freddie and I resembled each other. Freddie and I grinned because we knew it wasn’t true. Since Freddie was considerably prettier than I – and that was an understatement – I didn’t know if Maria’s comment was a compliment to me or an insult to Freddie. I decided to take it as the former.

We were there to see Ed, of course, but I had asked Pat to come because her mother had recently been diagnosed with Alzheimer’s as well. Thus far Pat was distraught over her mother’s condition and couldn’t accept it or find any meaningful way to interact with her mom. She was in the state of depression I had experienced during Ed’s earlier stages of the illness. One reason I was taking Pat to visit Ed, who was almost always in a joyous mood those days, was to show her that a demented person could still be a *happy* person. I thought that could help her accept her mom’s condition better.

Suddenly a new resident named Bob walked up, his white sweatshirt embossed with “University of Cincinnati” in large gold letters, hinting at his former career as a UC professor. He greeted us, acting like a one-man welcoming committee, just as though he’d been elected to that position by a group of his peers. He smiled as he raised his right hand and waved with enthusiasm.

“Hi! How are y’all?”

“We’re great, Bob. How are you this afternoon?”

“Fine,” he said. “I’m fine. I’m just fine. Y’all come right in.”

Having met Bob’s approval we went to the dining room, where we smelled baked beans overpowering whatever else must have been served for lunch. Then we saw Ed dressed in a pale blue Oxford cloth shirt, his gray tweed sport coat and black Dockers. He was dozing in a chair at

one of the tables; his two Care Bears were on the table in front of him. When I first toured the Alois Center I'd seen several residents asleep sitting up like that, heads resting on their chests. I'd been certain Ed would never become that debilitated. Well, he had. And I'd gotten used to that, too.

I put my hand on his shoulder and said his name loudly. He looked up and saw us, but was confused and started speaking Romanian.

"Kitty," I said. "We don't understand Romanian."

He answered something or other, still in Romanian.

"No, Kitty," I said. "Speak to us in English. Not Romanian."

"Oh, excuse me, Kitty" he said. "I'm so sorry. I didn't know I was speaking R-r-romanian."

Then I introduced Freddie and Pat and explained how we were all related. He immediately proclaimed that Pat and Freddie were sisters. Pat started to correct him, as she would have done with her mom, but I motioned for her to let it go. I'd mentioned to her that it was often wise not to correct demented people when they said something wrong, but to try to connect with them on their level.

Throughout the visit Ed couldn't remember Pat's name and so, being the refined gentleman he still was, he politely referred to her each time as 'The Lady.' Ed was pretty confused that day, but he was in a great mood and had a most pleasant conversation with us. And that was the very point I'd wanted Pat to get.

"The most interesting thing is going on here today," he told us cheerfully. "A famous Romanian poet, Miro Trestioreanu, has been all day in the garden talking."

"Oh, that's wonderful Kitty," I said, playing along. "What's he talking about?"

"I don't know," he answered. "I can't understand a word he's saying."

"How do you spell his name?" I asked.

"T-r-e-s-t-i-o-r-e-a-n-u," he slowly spelled the name.

I was more than a little surprised he was able to spell such a long complicated name and wondered if it was an actual Romanian poet. I asked him to repeat it and I wrote it down, planning to check it out on the Internet. I later discovered it was a real Romanian surname but there wasn't any notable poet by that name.

Then Ed changed the subject.

"You know," he whispered, an impish look on his face, "I don't just take to my r-r-room the spoons. I also take those little pillows from the sofas in the lobby."

"I know, Kitty," I laughed. "I've seen them in your room. You have a lot of fun taking those pillows, don't you?"

"Yes, he does," laughed Rhonda, who had just come over to give Ed his medicine. She'd overheard my last remark and, unlike some staff members, thought it was amusing that Ed took the pillows.

"Hey! Handsome! I see you have a lot of company today."

"Yes. I do. This is Ma-r-r-rie Marley – you know her well – and she brought with her these two ladies."

I introduced Freddie and Pat, and surprisingly, Rhonda also felt that Freddie and I resembled each other. Rhonda gave Ed two small yellow pills and a little cup of water. He swallowed the pills and handed the cup back.

"Nice meeting you guys," she said nodding at us. "We all just love Edward. He's so adorable."

"Oh! Thank you!" he said seriously, looking up at her.

She patted him on the back, then went to the adjoining table and had a little talk with Fred, at least as much as you could have a talk with Fred, and gave him some medicine, too.

The next order of business was photographs. We each posed with Ed and the two Care Bears. The photo of Ed and Freddie was the most appealing. Freddie had a unique way of dressing. Although she was fifty, five years younger than I, she usually dressed like a teenager. That day her short bleached hair was spiked and she was wearing earrings that dangled down to her shoulders. A low-cut hot-pink blouse with three rows of black sequins outlining the neck lay under a white jacket. In the picture she looked ultra-sexy and was sitting so close to Ed she was practically on his lap. She had her arm around his shoulder and was smiling girlishly, her green eyes twinkling. If I didn't know better, I'd have said she was flirting with him.

Ed's shirt was buttoned to the very top. It was interesting. The older he'd gotten, the more shirt buttons he buttoned. When he was young – if you consider the 62 years he had accumulated when I met him young – he left the top two unbuttoned, and he looked sexy. Later he became more conservative and left only the top one unbuttoned. A few years

after that, he started buttoning even the very top one. I'd tried to get him to leave the top one unbuttoned, but he'd never do it.

In the photo Ed had both forearms firmly planted on the table, one on each side of the Care Bears. One was lavender and white; the other, powder blue and white. Each had a red heart on its chest. He was staring straight into the camera.

We exchanged more pleasantries and listened to more unlikely stories from Ed. Then we said our good-byes and he accompanied us to the door, where he kissed our hands. Pat, who'd never experienced that 'gentlemanly' behavior from Ed, was pleasantly surprised.

"Come back soon," he said.

"We will."

"In an hour!" he said.

"Yes. In an hour!" I said.

"Superb!"

As we opened the door to leave he blew kisses at us.

About half way home Pat, sitting in the front passenger seat, quietly spoke up and said, "You know, Marie, I can see what you were talking about."

I turned off the radio and gave her my full attention.

"I dreaded going to visit him at first, but I'm glad we did. He *did* seem happy," she said, taking a drink of the Mountain Dew she'd gotten from the vending machine, "despite the fact that he was confused. He may not have known what day it is, who we are and where he is, but somehow that really didn't matter. Not from his perspective, anyway. I'm going to remember this the next time I go visit my mother. I'll try to look at things from her point of view instead of mine. She may be just as happy as Ed seems to be."

I was pleased that our visit seemed to have helped Pat begin to come to terms with her mother's condition. That's what I had hoped for.

Yet the photo of Freddie and Ed I took that day would also have a lasting, if unexpected importance. As fate would have it, I would outlive them both, and the picture would bring me great comfort in the future. Freddie, who had become my new phone companion, my one saving grace, would meet a tragic death just six months after Ed died. Having a horrible headache one night, she took too many of her husband's prescription morphine capsules and paid the ultimate price. It was such



a tragic accident. She was only 51. I was devastated and felt entirely alone in the world. In a way I was.

### **So Many Pockets, So Little Time**

“BINGO!” a woman hollered in a shrill voice.

I peeked into the activity room and saw Ed smiling, sitting on the far side of the long craft table. He looked like he was having a grand time. I didn’t want to interfere with his fun so I went over, pulled up a chair and sat down on his left side, the side with the real eye, so he could see me in his peripheral vision. Martha, a tiny, sweet-looking aide I hadn’t met before, was in charge of the small round bingo cage full of little balls, each with a letter and number on it. She seemed so young I wondered if she was a volunteer from one of the local high schools or something. She spun the cage, picked up the ball, and called out the combination loudly enough for even the most hearing-impaired resident – that would be Ed – to hear.

“B-6!”

Ed looked at his card intently then sang out sweetly, “Here ‘tis!” and covered the proper square with a red plastic marker.

I was glad he was enjoying himself so much, and quite frankly, surprised he was competent enough to play by himself. Martha had seated Lucy and Sylvia on either side of her, so she could lean over and help look for the numbers on their cards. She praised them lavishly and patted their hands when they had the number. Betty, at least ninety and almost as underweight as Ed, sat undisturbed amidst the players, constantly rubbing her hands together as though applying lotion to them. And the last one in the mix was Rose, who seemed as oblivious as Betty to what was going on around her. Yet the excitement and warmth in the room engulfed them nonetheless.

The game continued and each time Ed had the number he called out melodically with glee, “Here ‘tis.” I found it amusing and had to suppress a laugh. Martha seemed to find it funny, too, and looked in Ed’s direction, a smile on her face every time he voiced his little refrain.

“He’s darling,” she said, looking at me. “He must be a wonderful friend.”

*If she only knew.*

Sylvia yelled something, in what I would later find out was Portuguese, in a disgruntled tone of voice every time she didn't have the number. I could tell Ed was getting annoyed with her.

Finally, I guess he decided he'd had enough of her grouchiness because he said so loudly that it was embarrassing, "I just have one word to say!"

"What is it, Ed?" Martha asked, a concerned look on her face.

He pointed his shaky finger at Sylvia and shouted, "Enough!"

He was right. He did have just one word to say. Again, I had to control myself to keep from laughing, and it looked like Martha was stifling a laugh as well.

After the game ended, Ed and I walked to his room. His steps were slower and more hesitant than I'd ever seen, and he was so out of breath that he had to stop every few steps to rest. When we finally arrived in his room he sat down on the sofa. It was a good ten minutes before his breathing returned to normal. I was alarmed.

Although I typically stopped at the vending machine and got a candy bar and a Diet Coke for myself, that day I'd brought a treat for both of us. I dug into my new Brighton purse, which Ed loved because it had so many compartments – which I'd let him explore the week before – and took out two dark chocolate Hershey bars. My mouth began watering as I started peeling down the wrapper on his, and the juices increased as I repeated the action on my own.

Most of the time when I ate a candy bar I wolfed it down only to crave another one immediately. Ed, on the other hand, ate everything slowly. I decided to take my time and really enjoy the candy bar, vowing to take a bite only when he did. As we sat nibbling on our treat I realized that eating it that slowly allowed my taste buds to savor the flavor of the chocolate longer than when I ate it in my usual gluttonous way.

When we finished eating, I realized I'd forgotten to bring any 'props' for the visit. Usually I brought something to amuse Ed such as a new stuffed animal, a book with colorful pictures, some of my photographs, a CD with classical music or something like that. Those things engaged his mind, to the extent that was still possible, and gave us a focal point for interacting.

I was going to have to be creative or else the two of us would just end up staring at each other, making awkward small talk. Suddenly I

realized I was wearing a coat with numerous pockets I was sure he would *love* to explore.

It was a short, hooded, steel-gray Calvin Klein coat that was down filled and had a soft furry lining. First I showed him the lining and he caressed it with his hand, repeatedly commenting on how soft it was. Then he rubbed it against his face. Next I showed him the two side pockets. Almost every coat has side pockets but these were unusual because they had zippers. He 'oohed and aahed,' moving the zippers up and down, a look of wonder on his face. It was almost as though he'd never seen a zippered pocket before. Then I showed him something you really didn't often see. The outside of the left sleeve had a zippered pocket on it, too. That grabbed and held his attention for quite awhile. First he looked to see if there was anything inside the pocket (there wasn't) and then he played with that zipper, too. Then the hood caught his eye and he said how wonderful it was to have a hood in case it was raining. I was amazed he made that connection, especially considering how tired he was.

Having completed the tour of the coat's exterior, we began to explore its inside. All of a sudden Angel, who I thought was the most beautiful aide in the entire place, came in just to ask him if he needed anything. *What a wonderful facility.* He said he didn't but patted the empty space next to him on the sofa, inviting her to sit down. She did and he proudly showed her the pockets he'd discovered up to that point, except he forgot the one on the sleeve. She 'oohed' and 'aahed,' too.

As she was sitting there, Ed reached up and began to gently stroke her golden hair while they talked about the coat. She smiled and put her arm around his shoulder. It was a lovely and natural gesture and it warmed my heart. Aides and residents were often openly affectionate at Alois, but such behavior would have gotten him fired in his previous profession.

Alzheimer's patients often exhibit such a loss of inhibition, and in some cases, such as this one, it was a positive thing. In other cases the loss of inhibition is less acceptable. Earlier that day he'd taken off all his clothes in public again, that time in the Terrace living room.

When Angel got up to leave to tend to other residents, he kissed her hand and asked his usual question.

"When are you coming back?"

"Soon," she answered, knowing the drill.

“Wonderful!” he said.

We went back to our investigation of the coat. He’d already forgotten he’d investigated the zippered side pockets. In that respect his dementia made him so very easy to entertain. Soon we caught up and entered new territory. There was a pocket on the inside where a man’s breast pocket would be. That was unusual in itself for a woman’s coat, but that one was even more original because it, too, had a zipper. Ed looked at that for several seconds without speaking and then whispered slowly that he liked it. Just as he was starting to play with that zipper, his hands dropped into his lap, his face went blank and his head drooped. He was asleep.

I didn’t know whether I should wake him up or let him sleep. I ended up letting him sleep a few minutes then I gently shook his shoulder. He woke up and gradually became more alert.

“Kitty, you fell asleep!” I said lightheartedly.

“Oh, I’m so sorry. I didn’t know.”

That remark made me sad. Nonetheless, we went back to exploring the coat.

There were still two new pockets left. They were on the inside left near the bottom. One was square; the other, sewn on top of that one, was oblong and obviously meant to hold a cell phone. Unlike the others, which had zippers, those two fastened with snaps. When he saw them he was initially at a loss for words. A look of amazement on his face, he tried to unsnap them. His shaky hands couldn’t manage the small snaps, so I opened and closed them for him. He stared at them with astonishment, then smiled at me and told me *twice* how happy he was that I had such a wonderful coat. I was touched that he was happy *for me*. That was so typical of Ed. Instead of saying how happy he was to play with the coat, he said how happy he was that *I had it*. As I left I felt loved. I was also happy I’d been able to bring him so much joy with a simple coat.

On the drive home I listened to Haydn’s Clock Symphony. I found myself smiling while thinking back on the visit, especially Ed’s delight at the zippered breast pocket. Then a more somber thought came to my mind. I wondered how long his ability to enjoy my visits would continue. If he lived long enough he might lose the ability to recognize me, let alone enjoy our little games. I wanted him to live as long as

possible but I knew the longer he lived the more demented he would become. And there was nothing I could do about it.

### **A Precious Gift**

I'd just come back from visiting Ed when the phone rang. It was a female voice I recognized immediately. It was Sandy Panther from the American Academy of Family Physicians. She was calling to do a pre-interview with me for the Academy's grant writing job. Although I hadn't expected this phone interview, it was going well and I was excited about the possibility of getting the position. But then she mentioned that although the job could be done by telecommuting, the new employee would have to be in Kansas City for the first three to six months to get to know the organization, the employees and the programs. That would mean leaving Ed all alone at Alois. My heart sank. Since the budget cuts had put my wonderful job as a grant writer at UC in jeopardy, I needed the position. So I lied and told her that a few months in Kansas wouldn't be a problem.

*God! What a problem that would be.*

When I got off the phone I sat at my tiny desk in my new burgundy sweats finishing my coffee and asked myself how I could possibly abandon Ed for three to six months even if I flew back every few weeks to visit him. We couldn't stay in touch by phone because he wasn't capable of talking on the phone anymore. A computer hookup wouldn't work either – I didn't think he'd comprehend that I was the image on the monitor. But I needed the job. Badly.

It was a tough dilemma. I was excited by the opportunity for such a wonderful career advancement, yet my emotional need and moral duty to stay with Ed was equally strong. I had no idea what I was going to do. I finally decided I'd tell Ed about the phone interview and the planned in-person interview, but wouldn't mention the initial residency requirement in Kansas. I assumed he wouldn't understand the implications anyway. A few weeks earlier I had mentioned that I was looking for a new job and he'd reacted with complete incomprehension. I could have told him that I did my laundry or went to the dentist or fell down the stairs. It would have been all the same to him.

When I arrived I went directly to Ed's room, head down, avoiding eye contact with the various residents and staff I passed. When I entered his room I found he was in his bathroom so I sat down in the rocking chair

to wait for him. I was suddenly overwhelmed with sadness. Here I was with the best news of my entire career and I couldn't really share it with the person I loved the most.

Soon he came out, a determined look on his face, steadily pushing his walker, feet moving in deliberate, evenly-measured steps, slapping down on the linoleum floor. Janelle had dressed him nicely in the beautiful navy cardigan I had given him one year for his birthday, navy Dockers, and a pale yellow shirt. He greeted me enthusiastically and told me how happy he was to see me and how beautiful I was. He maneuvered to the sofa and moved aside two big bunnies so he'd have a place to sit. Then he picked up The Little Yellow One, ever his favorite, put it on his lap, looked at it affectionately, and started 'padding' it.

"I have to tell you something that's very important, Kitty," I said, mindlessly picking up Adorable and feeling guilty that I was only going to tell him part of the story.

"Oh! Please. Tell me!" he said, continuing to 'pad' the little animal.

"Well, the American Academy of Family Physicians has a job opening for a grant writer and I applied. It would be a *wonderful* job for me," I said, rocking back and forth and keeping my words simple.

I stopped rocking and just waited for his response, expecting something totally unrelated like "It's nice that we live here in Romania," or "Your shoes are *so* beautiful," or "That lady on the television is the Pope."

But he didn't say anything like that.

"Oh! Kitty! They will hire you," he said, putting The Little Yellow One down and looking me straight in the eye. "With your background and qualifications," he went on, "with all your experience and the tremendous success you've had over the years, they will certainly hire you."

I just stared at him.

"Don't worry. You will get the job," he continued immediately, his eyes tearing up. "I'm so happy for you, little Kitty," he said, his voice cracking a little. "I'm sure they'll hire you."

I was profoundly touched. Not only was he talking like the highly educated man he was, he also cared about me so much that he had tears in his eyes just thinking that something good was going to happen to me.

"Congratulations!" he said. "You will get the job. I'm one hundred percent certain."

“Thank you,” I whispered. “It’s my dream job.”

I didn’t know what else to say. For that brief moment I’d had my ‘old Ed’ back. What a precious and unexpected gift.

I drove home carefully over the snow that had fallen the night before and was now heavily packed on the highway from all the morning’s traffic. When I got home I lay on the sofa. Peter stretched out across my chest and rested his head on my neck. I petted him and he licked my face continually until I finally made him stop. My eyes fell upon the glass vases on the bookshelf across from the sofa. Every single one was related to Ed in some way or other, and each evoked memories of times gone by.

That night Ruby called to update me on Ed’s condition and I was upset by what she told me. Ed was having so much trouble breathing just sitting up in a chair that Dr. Zakem had decided to put him on oxygen. They’d start it the following day.

My mood instantly became somber. I knew this meant that Ed had taken another step closer to the end.

## Chapter 13: Come Back Early Today (2006 – 2007)

### Ah . . . She Loved Me

I had a beautiful, relaxed drive to Alois that lazy Sunday afternoon. I wandered into Ed's room and found he was in his bathroom, so I sat in the rocker and waited. My eyes were drawn, as was often the case, to his stuffed animal collection, which had grown quite large. On the sofa I noticed that he, or possibly an aide, had positioned them in a rather artistic grouping. The giant two-foot bunny was in the back and the others had been placed in a semicircle around it. There was The Little Yellow One, of course, and Adorable. Then the others, who didn't have names, because two were the most he could manage to think of and remember. There were two medium-sized blue bunnies, the two Care Bears, and a tiny 'Uncle Sam' teddy bear wearing a red and white striped top hat.

They all sat as though posing for a group photo. In fact I had photographed them many times. I even had a lovely picture of Ed kissing Adorable. Lastly, there was the battery-operated 'breathing puppy' in its little bed on the coffee table. It was so cute I'd almost gotten one for myself, too. Ed once told me the first thing he did when he entered his room was check to see if the puppy was still 'breathing.' It was just a matter of weeks until I'd find myself doing the same with Ed.

That day I'd decided to show Ed the cards and photos I'd found in his storage unit. It was Rosa's idea – I never would have thought of doing that myself. I got up and turned on the black pole lamps at each end of the sofa. The one on the left didn't come on. *Reminds me – I have to get a new bulb.* So I went to get the white lamp from the other corner of the room and put it at the left end of the sofa. Having illuminated the room as much as possible to compensate for Ed's poor eyesight, I was ready to start the show.



"Kitty!" he exclaimed, coming out of the bathroom. "I'm so happy to see you. You are *so* beautiful!"

Then he sat down, careful not to disturb the little animals.

"Hi, Kitty. I found some old photos and cards I sent you many years ago and I'm going to show them to you today."

"Marvelous! Superb!" he answered, using the words he always used when he was happy about something.

I decided to start with the cards. Although he was no longer able to read books or the newspaper, I hoped he'd still be capable of reading the cards. He was, and he even seemed to understand what he read. He laughed at the funny ones and responded more seriously to the others.

After he'd seen them all he looked up at me and said in a reverent tone of voice, "Kitty, I am *so* touched that you kept these cards all these years."

I didn't even try explaining that he was the one who had kept them.

Next we looked at the photographs. Some were from his childhood. There was one of him around age six wearing a sailor suit and posing with his father, and another with his grandparents, sitting on a bench in a beautiful park. I was awestruck when I suddenly realized some of those photographs were more than eighty years old. Then there were several pictures of us from the '80s and '90s. There were also photos of him with a whole variety of people I didn't know. I guessed they were different Romanian friends and relatives. Probably some previous lovers, too.

He was drawn to the photos just as much as he was to the cards, studying each with interest. The last one was a picture of him with a woman standing behind him. She had her hands on his shoulders and her head was peeking around his, facing the camera.

"Ah . . . She loved me," he murmured, an affectionate expression on his face. He kept looking at the photo.

"What are you thinking?" I asked when he didn't say anything more.

"I'm thinking of love," he whispered.

"That woman is me and I still love you."

He looked up and gazed into my eyes the way he did when we were lovers. I couldn't tell if he was in the past or the present. I decided it didn't matter.

**A Small State of Bliss**

That was it. He lived only in the present. I realized that about Ed one day while I was at Wendy's enjoying my usual post-visit chocolate Frosty. Ed lived only in the present, and that was something we could all benefit from. He didn't do it because of any particular wisdom, though. It was because of the disease. He didn't fret over yesterday because he couldn't remember it. And he didn't worry about tomorrow because he didn't have the mental capacity to do so. It reminded me of something he used to tell me: "*Little* Kitty, there are so many things in life to worry about without worrying about things that haven't happened yet." Good advice that, unfortunately, I'd never been able to internalize. But I was contented he'd achieved at least that small state of bliss, not that I would wish its cause upon my worst enemy.

**Such a Brilliant Mind – Such Simple Pleasures**

When I arrived one day, Ed was in the Terrace TV room sitting on a folding chair playing balloon volleyball with Fred and two female residents I didn't know. Another female resident was there, too, but she was just watching. I never thought I'd see the day when Dr. Edward Theodoru would participate in a sport. Nor would anyone else who ever knew him. Not wanting to disrupt Ed's activity time, I sat on the floor beside him to watch. He was really quite good at it. Of the four residents playing he was the most coordinated and most enthusiastic.

Joan, another of the Terrace's precious aides, was directing the game. Petite, blond and blue-eyed, she was full of energy. Joan never walked anywhere. She rushed. Joan could shower, shave and dress Ed in half the time it took the other aides. And she was a firm believer in therapeutic touch, frequently putting her arm around Ed, rubbing his back, patting his cheek, or squeezing his hand.

Every time the big yellow balloon went flying toward Fred he just stared at it like he stared at everything and everyone. Joan touched Fred's arm as she stooped to pick up the balloon. Then she put it in his lap and put his hand on it.

"That's good, Fred!" she said. "Good for you!"

Then she threw it toward another resident. When she lobbed it Ed's way, he got a determined look on his face, then he joined his hands together and stretched out his arms. When the balloon got within

striking range he hit it, or 'beat it' as he said, sending it flying across the room. Twice he hit it so hard it hurtled into the hallway.

"Good job, Ed!" Joan shouted while dashing out to get the balloon. "Extra points for you!"

"Oh! Marvelous!" he said. "Throw it r-r-right here and I'll beat it again."

My heart ached seeing Ed so elated, sitting in a nursing home batting around a balloon. Just a year before he would have spit on anyone who dared suggest he engage in that type of game or any game for that matter. But I realized that, generally speaking, he was a lot happier than I'd seen him in years. That thought brought me comfort as he hit the balloon into the hall again, another big smile on his face.

### **It's Christmas and He's Still Here**

It was mid-December and the Alois Center was all abuzz with Christmas preparations. The lobby and other common areas were brightly decked out with splendidly-decorated Christmas trees, and many of the lamp tables held tasteful holiday decorations, inviting all to join in celebrating the season. A delicate crèche sat atop the baby grand, and a garland was attached to the Courtyard's living room fireplace mantle. Large wreaths with pine cones, berries and red ribbons hung on the doors to each unit, and the doors of many resident rooms were adorned with candy canes or holiday craft items Jan had helped the residents make. In the lobby, the radio was tuned to a station playing Christmas carols, the volume turned up so the music would fill the entire area. The smell of pine trees was in the air and, combined with the music, evoked memories of Christmases past. A Christmas carol sing-along in the Courtyard dining room made things especially festive. Visitors were dashing in and out carrying brightly wrapped packages. Many had sweet little children in tow, undoubtedly residents' grandchildren making their Christmas visits to grandma or grandpa.

Every ten to fifteen minutes the name of yet another winner in the Center's holiday raffle was broadcast over the loudspeaker. They held a raffle every year, with the gifts provided by residents' families. It was a creative way to let families thank the staff for all the wonderful care they'd given their loved ones throughout the year. There were so many announcements I was sure they arranged it so every staff member would win something.

I'm not sure Ed really noticed the festivities. His physical health was declining noticeably. More often than not I'd find him dozing in a chair or on the sofa, and that day I found him in his room, asleep in a *wheelchair*. I was shocked and, before even trying to wake him, I went to inquire about why he was in a wheelchair. Apparently he'd been particularly weak since my previous visit, was getting extremely fatigued and had trouble breathing when walking. So the head nurse and the hospice nurse had discussed the situation and decided he'd be much better off in a wheelchair. I was sad. I felt sure he'd never walk again. I even wondered if they'd soon have to move him to the Gardens. The unit I always thought of as the one where Alois residents went to die.

Dr. Smucker had said that if Ed were still around at Christmas, chances were that he'd survive a 'considerable' time after. But given this new alarming and undeniable indication that Ed's physical health was rapidly failing, I wasn't entirely convinced Doug was right, and despite all the excitement at the Center, I didn't exactly feel like celebrating Christmas.

### **The Innate Capacity to Feel Joy**

When I entered Ed's room he was asleep and actually snoring in his wheelchair. It took quite a bit of effort to wake him. But after a few moments his eyes lit up, he lifted his head and said, "Oh! It's you. Oh! I'm so happy to see you. You're an angel. I'm overwhelmed to see you. Oh! I'm overwhelmed!"

"I'm happy to see you, too," I said, sitting down on the sofa, wondering what was causing such an outpouring of joy and affection.

Then he looked in my eyes and said in a most serious tone of voice, "Since I became in such high admiration of you, other beauties didn't exist."

His eyes were shining, his face glowed, and he held my hand, kissing it again and again. I wanted the joy he felt to last, and so I picked up Adorable and put him in his lap, hoping that would elate him even more.

"Oh. The *little* one," he said, looking at Adorable. "I love him so much," he added, picking up the bunny and holding it tightly against his chest.

It was as though he'd never seen Adorable before. His eyes glistened as he caressed the little animal and kissed its head several times. Then he

carefully put Adorable on the sofa, turned to me, and kissed my hand again. His happiness at seeing me, and his affection for Adorable touched me deeply and I realized that no matter how demented Ed might be, he still had the innate capacity to feel joy. It made me feel joyous too.

### **I Love You**

It is often said that animals and children reach dementia patients on a level people cannot. Every time Ed saw Peter he said, "Oh, the *little* one. I love him so much."

I often took Peter to Alois. And most of the time, as soon as we'd enter the lobby, he was the center of attention. Tom would suddenly smile, which made me smile, too. Carol would cradle her bear in her left arm, lean down, and pet Peter with her right hand. I knew Joyce liked Peter but since her eyesight was so poor she couldn't see him. So I'd pick him up and hold him close to her face. With a vacant expression, she'd pet his head. Often he responded by licking her face, which she'd allow until he started licking her right on her lips. Then she'd turn her head away in disgust. Then there was Jane. The one Peter had gotten to talk to me for the first time. Her face, too, would light up every time she saw him and she'd lean down to pet him.

"What's his *name*?" she'd whisper.

"Peter."

"Peter?"

"Yes. Peter," I'd confirm for the hundredth time.

One day we ran into Janelle, who stopped me in the hall.

"Hi, Marie," Janelle said, her ever present tranquil smile beaming while she petted Peter. "I wanted to ask you to bring back the slacks Ed was wearing when he first came here."

"Why?"

I couldn't imagine any reason. He'd gained weight and they'd had me bring him larger pants.

"Well, he's lost some weight lately and his pants are just hanging on him."

*Oh my God! I hadn't even noticed.*

"His appetite has worsened, and the aides have had to start feeding him," she said.

I was alarmed. I'd seen the aides feeding other residents, and most of them were in pretty bad shape. I couldn't believe Ed had joined their ranks.

I told her I'd bring the slacks, and continued down to Ed's room, convincing myself that he was not eating well because he enjoyed the attention from the pretty young girls who were feeding him. But down deep I was afraid it was actually a disturbing development, and I kept hearing Dr. Smucker's words in my head: "They just start eating and drinking less and sleeping more . . ."

I found Ed dressed in black sweat pants and a mustard yellow sweat shirt, an atrocious color that made his face look horridly sallow. I really wished they wouldn't put it on him. I was tempted to steal it some day and throw it away. He was dozing in his wheelchair as had become usual by that time.

"Hi, Kitty. Here we are," I said, certain my voice was loud enough to awaken him.

He lifted his head and saw us.

"Oh, the *little* one," he said, emphasizing 'little,' and perking right up. "Pe-tair. *Little* Pe-tair. Come here," he said, reaching out his arms. "Let me see you."

He didn't even look at me.

"*Little* Pe-tair, come here," he repeated.

Peter ran to Ed.

"Hi, Kitty," he said, finally turning his attention to me. "Can I hold him?"

"Sure."

I put '*little* Pe-tair' on Ed's lap as I had done so many times before, expecting him to jump down in no time as he always did. Ed started stroking him slowly, his hand starting on Peter's head and moving down his back all the way to his tail. Then back to his head again and slowly down his back. I sat down in the rocking chair, sure Peter would squirm, jump down and come to me.

But he didn't.

Peter just stretched out, closed those big brown eyes, and rested his chin on Ed's arm.

Mary came in, wearing a lovely sunflower blue pullover and navy slacks. She emptied the waste basket.

"Hi, Peter," she said in the tone of voice people often use when talking to a child.

Almost all the staff knew Peter by name.

"Looks like you've got a good buddy there, Edward," Mary laughed. "I bet he'd like to move in here with you."

Ed laughed, too. His laugh sounded artificial. That was how I knew he hadn't understood what she'd said and only laughed because she had.

"I have to go on to the next room now, Edward."

"When are you coming back?" he asked.

"Soon," she promised.

"Wonderful!"

After Mary left, Peter put his chin back on Ed's arm, and Ed resumed stroking him.

"Does he like it when I 'pad' him?" Ed asked, looking at me expectantly.

"Yes, he likes to be petted."

"Oh, I'm so happy he's happy when I'm 'padding' him."

I watched them while I rocked, wondering what had made Peter stay on Ed's lap. He'd *never* done that before. It worried me.

*What does Peter know that I don't?*

When it was time to leave, I started putting on my jacket.

"I love you," Ed said.

I was startled. We'd never said those words to each other. We knew it and never felt the need to say it.

"I love you, too," I said simply, looking in his eyes.

"When are you coming back?"

"Tomorrow," I answered, zipping up my jacket.

"Marvelous!"

### **Come Back Early Today**

I was ready to scream at my work. Even though it was Saturday I needed to work on a grant. I was behind, but I was so burned out that I decided to drop it and go visit Ed. I'd been visiting only on Sundays because I'd been preoccupied with work. I just hadn't had time to visit Ed more often. But that day I decided to go see Ed anyway although it was Saturday.

I also decided to dress stylishly for a change. I donned my brand new dress jeans, a black turtleneck, the matching jeans jacket, and a smart

pair of dress boots. Then I topped it off with a bronze bolo tie sporting a contemporary Southwest design, a piece of jewelry I'd bought twenty years before in Santa Fe that never failed to bring compliments. It felt good to dress up. I did it so rarely.

During the drive out I felt liberated. It was exhilarating to be free from my mind-numbing work and worries about the job interview. Kansas City still hadn't called to set up the in-person interview, and I was beginning to worry that they'd already hired someone else. When I arrived I got out of my toasty car and stepped into the raw ten degree air. If you factored in the whipping wind, it felt like five below. I hurried into the building, my breath visible in little puffs trailing behind me.

Ed was in bed asleep.

*They must have let him skip breakfast.*

He was lying on his back with his mouth open. His beige blanket was pulled up under his chin, covering every square inch of him except his head. He was often asleep when I arrived, but I was usually able to wake him up and get him out of bed for a lively visit. So I called out his name. He opened his eyes then looked over at Mary, who was silently mopping the floor.

"Isn't she *beautiful*?" he said, referring to me.

Mary smiled and nodded.

I walked over to his bed and handed him the large white teddy bear with curly fur I'd gotten for him at Walgreen's the day before on my way home from work. Never tiring of receiving new stuffed animals, he took it in his arms and smiled like a four-year-old who just came downstairs on Christmas morning to discover a huge pile of presents under the tree. He hugged the bear to his chest, caressed it and kissed it several times. Mary discretely left, silently closing the door behind her.

"Do you like it?" I asked.

*"Like it?"* I'm overcome with affection for him."

"Do you want to get up?" I asked.

"Sleepy!" he called out loudly in a childlike voice.

That was a first. I sat down on the bed and held his hand. We hadn't held hands since we were romantically involved all those years ago. But I felt like holding his hand that day. He dozed intermittently, looking so tiny and frail in his bed.

His breathing seemed strange. I'd never seen him breathe like that. He took several short breaths – huffing and puffing like someone who'd



just run up several flights of stairs – then he stopped breathing completely for several seconds. Each time he stopped breathing, I watched his chest intently, waiting to make sure it started moving again.

*This is how it will end someday. He will be dozing like this and breathing like this and stopping to breathe like this and simply not take another breath.*

We talked in-between his intermittent dozing. Nothing important. We talked about whether he had breakfast that day, he told me how beautiful I was, and he talked about having seen his father the night before. I wanted to tell him Saddam had been executed recently, something that would have captured his full attention in earlier days, but I was sure he wouldn't understand it, and so I didn't tell him. Angel came in to check on him, but seeing how we were sitting holding hands, excused herself and said she'd return later. He told me how wonderful it was that we were living in Romania and that the facility where he was living was free.

"I have to go home now," I said after awhile. I let go of his hand reluctantly and got up to put on my coat.

"When are you coming back?"

"Tomorrow," I answered, getting my gloves from my purse.

But instead of saying, "Marvelous!" as always, he suddenly looked disappointed, as though I'd said I wasn't coming back for a month.

"*Tomorrow?*" he asked. "What do you have to do that's so important you can't come back until *tomorrow?*"

I didn't know what to say.

"Well, when do you *want* me to come back?" I finally asked.

"*Today!*"

"Okay," I said, playing along. "I'll come back today."

"*Early* today!" he added firmly.

"Yes," I said. "I'll come back *early* today!"

"Marvelous!" he said.

He smiled, obviously convinced by my statement. He kissed my hand, and when I left I turned and blew kisses to him and he blew kisses back to me.

As I walked toward the lobby door I obsessed about his breathing. When I reached the door, instead of punching in the numbers on the keypad I made an abrupt u-turn and headed for the nurse's station. I was relieved to see that Rhonda, her abundant makeup bringing her face to life, was on duty. She always told it like it was and I could always count

on her to give me straight answers. It was obvious she was deeply attached to Ed – or ‘Theodore’ as she called him. I told her the details of how he was breathing, expecting her to do something about it or call Dr. Zakem, who would do something.

“Oh,” she said, smiling, putting down her pen and swiveling her chair, turning toward me. “He’s just breathing like that because he’s excited you’re here. He was breathing fine a while ago. Don’t worry,” she added. “We’ll take good care of him.”

Her answer didn’t relieve me, but I couldn’t think of anything more to say or do. Back down the hallway I went, then through the lobby, barely conscious of the residents and staff I passed along the way. As I left the building, I contemplated the fact that Gerald Ford had died just two days earlier at age 93. Reagan, another of Ed’s heroes, had also died at age 93.

Ed was 93.

I had to admit I was a little superstitious.

I tried to put those thoughts out of my mind as I drove the familiar route home, listening to Dr. Gary Clemmons on *Pet Talk* and thinking about my photography, my new Dell, the job interview I still hoped would be scheduled – anything but Ed’s breathing.

I didn’t go back to visit Ed again that day, of course. I’d said it just to please him as I’d always done. I’d always known he’d never know the difference.

I woke up at 8:30 the next morning, much later than usual. I threw on my steel-gray down jacket, the one Ed had loved exploring a few weeks earlier, and took Peter out into the cold darkness. The Sterling Way streetlights were burning but all the neighbors’ windows were black. When I came back in I dried the outdoor slush from Peter’s feet and took off my boots, dropping them one at a time on the white entryway tiles.

I made coffee and enjoyed that first cup while sitting at my desk, cluttered with papers everywhere except the space my new Dell commanded. I opened my journal file and started typing, keys softly clacking away, barely audible in the otherwise silent house. I wrote about how worrisome his breathing was, how Rhonda made light of it, how I thought she didn’t know what she was talking about. It didn’t occur to me that she might have been holding something back. I noted how odd it was that Ed had insisted I come back “today – *early* today.”

I paused to get my second cup of coffee. How much time did he have left? A year? More? Less? Who knew? I knew it was hard to predict with Alzheimer's. I finished my journal entry, revised it several times, true to my obsessive-compulsive nature, then clicked 'Save.' Another day's entry was complete.

I turned my attention to my grant. As I began, the jingling of my little Sanyo startled me. I walked over and picked it up from the file cabinet. Caller ID said it was the Alois Center.

I flipped open the phone.

"Hello," I said.

"Hello, is this Marie Marley?" asked a woman whose voice I didn't recognize.

"Yes, it is," I answered.

"This is Joyce, from the Alois Center. I'm afraid I have bad news for you."

*Oh my God! Ed's fallen out of his wheelchair and injured his head.*

"Edward is gone," she said.

## Epilogue (2007 - 2011)

I drove out to Alois to see him with trepidation. I'd never seen a dead body before. The nurse assured me he looked fine – just like he was sleeping – and she was right. I put the white curly-furred teddy bear I'd given him the previous day on his chest. When Mr. Clepper arrived I asked him to cremate the bear with Ed. As I left Ed's room for the last time ever, I turned slightly and whispered over my shoulder, "Good-bye, Kitty."

On my way back to the parking lot I encountered Nancy, the last aide who'd seen him alive. Her eyes were vacant as she whispered to me that he'd seemed fine that morning. That she showered and shaved him, then he'd kissed her hand, took a breath and died. My dear Ed had been a gentleman to the very end.

In the days following Ed's death my brain functioned at about fifty percent. I kept losing important papers, like my notes for the eulogy, and I forgot a grant deadline. I'd never ever missed a deadline before. Sometimes I didn't know what day it was; I missed a doctor's appointment because I showed up on Tuesday instead of Monday. I got lost driving home from work *twice* and even picked up the phone one morning to call Alois to ask how Ed was doing.

As planned I held the memorial service at the Alois Center. It was standing room only. After the service a middle-aged man came up and introduced himself. His name, Ken Colston, was familiar. I thought for a moment and then remembered Ed talking about him often way back when he was teaching at Northern Kentucky University. Ed always said that Ken was the brightest and most conscientious student he'd ever had, and I recalled that Ed had helped get Ken to France for a year abroad.

At the time of Ed's memorial service, Ken was the head of the English Department at Thomas Jefferson School, a private boarding and day school in St. Louis. He said he wanted me to know that Ed was one of

the greatest teachers he'd ever known and that this meant something given that he'd "attended more universities than he had fingers." Ed had taught him inerrant good taste; taught him to discern the enduring, the careful, the crafted, beautiful and true in Western civilization; taught him to speak French virtually like a native. But most importantly, he said Ed had changed his life by making it possible for him to spend that time in France. It had been the experience of a lifetime, the experience that formed him firmly and forever as a scholar and – like Ed – a gentleman. And though thirty years had passed since his first class with Ed, since the day he was first exposed to that striking Theodoru intellect, he said that "Hardly a day goes by in my own teaching that some observation, phrase, or insight of Ed's does not come to my very lips. All of this," he said, "is Ed's legacy as a professor." It meant a lot to me to know that Ed had had such a profound and positive influence on someone else.

Shortly thereafter, Teresa got married and I was her Maid of Honor. At the reception I had to struggle mightily to hold back tears. I realized it brings great sorrow to witness other people's joy during a time of personal grief.

But as they say, when one door closes another opens. And indeed, two weeks after Ed's death, the American Academy of Family Physicians finally called me to come for that interview in Kansas. Thirty minutes before my 5:00 PM flight, Delta announced that it was cancelled. I called the Academy to tell them, and they said they'd reschedule the interview. But since it had taken them so many weeks to schedule it in the first place, I made a daring decision. On the spot. I told them I was going to *drive there. The whole 615 miles.*

I drove in the dark through heavy snow and sleet all evening and all night – nearly twelve hours, including two rest stops – to get to Kansas in time for the interview at 10:00 AM the next morning. Just before I arrived I ducked into a gas station restroom and put on my interview clothes – the same gray-flecked suit and burgundy blouse I'd worn when I had breakfast with Sandy Panther. If nothing else, the fact that I'd driven there was bound to let them know how much I wanted the position. I was high from all the coffee I'd had along the way and hoped I wasn't being obnoxious during the interview.

Apparently not, because four days later Irene Wrzesien from the Academy's Human Resources Department called to offer me the job. I

was so ecstatic I pranced around the living room while talking to her. Ed had been right when he so adamantly predicted that they'd hire me.

I'd worked at the University of Cincinnati for thirty years – long enough to be able to retire – and I did. My department chair was sorry to see me leave, but he understood it was a career move I had to make.

Since Ed was gone I no longer had any reason to remain in Cincinnati, so I decided to move to Kansas. I wanted to be physically present at the Academy. I wanted to get to know my colleagues. I wanted to be a part of the organization. I wanted to *belong*. I was anxious about leaving my job, my friends, and my home, but then I realized that when *Ed* was my age, he'd given up *everything* to come to this country. At least I didn't have to relinquish my language, my culture, my possessions and all my money. Just thinking about that made my move seem more manageable.

As I drove to Kansas '*Little Pe-tair*' lay contentedly snoozing beside me on the passenger seat, his enormous brown eyes closed. He had not a care in the world. Didn't know where we were going, didn't know we were leaving Cincinnati forever, and wouldn't have cared anyway as long as he was with me.

My new life was tremendously challenging and required my full attention. This took my mind off my loss as much as anything could. It would have been so much more difficult had I remained in Cincinnati. As it was, I simply didn't have time to wallow in my grief. Almost everything was new. I had to find a new home in a new city and adjust to a new job and new colleagues. What's more, I had to make new friends. My only physical carryover – other than my belongings – was Peter. He was a tremendous comfort to me in the months and years that followed.

When I arrived and moved into the house I'd rented during a trip in mid-March, I created a series of new spaces touched by Ed. I placed his bright red, white and black patterned Kilim area rug in my bedroom, where it adorns the floor next to my bed and welcomes me every evening. I hung two framed photos of Ed over my dresser. In one, taken when he was seventy, he appears at his most proud and professorial. The other is the picture I took of him smiling broadly sitting beside the violinist at the Alois Center. Both bring me pleasure when they catch my eye as I'm crossing the room.

I hung the deep red Romanian fringed cloth in my kitchen. It's a gentle reminder of Ed every time I pass by. I put the ruby, rose and pink Venetian vase in the center of the Scandinavian dining room table I bought just after moving. I'd purchased the vase when we vacationed in Italy all those years ago. It always gets lavish compliments from my guests.

In my study, a small photo of Ed sits on my desk, and one of his favorite prints, Klee's *Blaue Nacht*, hangs on the opposite wall. I smile whenever I look at it, and I still remember that day more than thirty years ago when we went to Pages and Prints in Clifton to have it framed.

In the living room I placed another of Ed's distinctive area rugs in front of my fireplace, where it complements the colored tiles, drawing ones eyes to the fire. *Above* the fireplace I put the vibrant print by a Venetian artist that I'd bought during our trip to Italy. Then, on a lamp table, I arranged two of Ed's small vases with a colorful plate I'd given him as a memento from our Hilton Head trip. When I walk through the room, these objects elicit memories of those two vacations – the first during our romantic relationship; the other, many years later.

These memories of Ed all around me are not a way of clinging to the past. Rather, they comfort me and encourage me to be confident in going forward with my new life.

Moving and getting settled in was nerve-racking and mentally and physically exhausting. What I really needed was what every professional woman needs – a wife. But I didn't have one, so I managed on my own. I'd thought of bringing Freddie out from Toledo for a week to help me, but was afraid my little sister would require more of my time to entertain her than she'd spend assisting me. Had I known she'd meet a tragic death just a few months later, I'd have flown her out for sure, just to spend some precious time with her.

My most challenging endeavor was making new friends. I'm rather shy around people I don't know and have always found socializing difficult. I decided to start by inviting people at work to lunch one at a time, hoping that would lead to further get-togethers with some of them. It turns out that I have *more* friends and *closer* friends in Kansas than I ever had in Cincinnati. I think that's because it requires that many close friends to fill the colossal void Ed left.

I most cherish the relationship I developed with the Nyugen family – Tom and Teresa and their two beautiful children. Tom and Teresa are

the Vietnamese owners of my nail salon. They pamper me, tease me and give me chocolate. What more could I want? And they left their hectic shop – something they almost *never* do – to come visit me both times I was in the hospital recently. The first time the children stood at attention at my bedside and sang to me. Five-year-old Mai sang a song about Jesus, and her nine-year-old brother, Minh, sang *Home on the Range*. I felt like laughing and crying both at the same time.

Our relationship goes to show you *never know* what stranger might become a cherished friend. While I purposely sought out friendships with people at work, these astonishing people just fell into my life. I don't know why they care about me so much but they do and I love them deeply.

During the dead of winter my first year in Kansas, when the temperature often dropped well below zero at night and the wind howled ferociously – we *were* in Kansas after all, where the wind is famous for its brutality – I was feeling a little down one day and decided to go Land of Paws just to *play* with some puppies. One hour later I was back at my house with an adorable eight-week-old Shih Tzu puppy I'd precipitously purchased and named Joey. Joey is an extremely playful puppy, and deserves the affectionate nickname I gave him: 'Silly Puppy.' Ed would have loved little Joey *so* much.

Now that there's a puppy in the house, Peter has become the elder statesman. Two years ago the vet discovered he had a malignant tumor taking up the space of two small oranges in his chest. Fortunately it was a kind of cancer that doesn't spread. So even though he was 14 at the time, I had the tumor removed and he was pronounced cured. No radiation treatments. No chemo. Simply cured. He's now 16, older than Shih Tzus typically live.

Having experienced the deaths of my mother, Ed and Freddie within an eighteen-month period, sometimes I feel like I'd rather die myself than have to go through Peter's death, which is certainly approaching. Because in my mind Peter stands for all three of them. When he goes it will be like they have died all over again. But I know I wouldn't really rather die myself. But it is a feeling I have sometimes.

As I'm sitting here writing this epilogue, more than ten years have passed since that fateful evening Ed was found driving on the wrong side of the road. I was only 50 then; now I'm into my 60s. The years have gone by slowly.



I still miss Ed sometimes. I wish he were here and I could tell him once more that I love him and I could hold his hand one more time and I could have the violinist come and play for him again. I wish he could see my lovely new home and know about my new job. I wish he could see his beloved Peter again and meet my new silly puppy, Joey. I wish I could hear him say, "Marvelous, Kitty! Superb! What a wonderful new house and job. What an *amazing* little puppy! Brava!" I guess I'll just have to settle for hearing it in my mind and feeling it in my heart. I know it's what he would say if he were here. And he would kiss my hand as he said it.



## Marie Marley, PhD

Dr. Marie Marley is an expert grant writer who, over the years, acquired a keen understanding of many geriatric topics, including dementia, but none of that could have prepared her for the sometimes heartbreaking demands of loving and caring for a person with Alzheimer's disease. *Come Back Early Today* is Marie's first foray into creative nonfiction, where she describes



her remarkable relationship with Dr. Edward Theodoru. Marie has been a grant writer at both the University of Cincinnati's Department of Family Medicine and the American Academy of Family Physicians. She lives in Olathe, Kansas with her Shih Tzu, Peter, whom Ed loved dearly, and her younger pup, Joey, whom Ed would have been so delighted to meet.

