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May 1, 2009

THE WOMEN IN THE PICTURE: A NARRATIVE OF THREE UNCOMMON WOMEN

Nancie M. Hazell

This project is a triptych of narratives illustrating the lives of the three women who most influenced my life: my aunt, my mother, and my best friend. These women not only inspired my life choices, but serve as examples of what any woman can accomplish.

Helen “Snooker” Hamilton grew up in suburban Philadelphia. Although she was a nationally ranked amateur tennis player, she followed in her older sister’s footsteps when she decided to become a nurse. She moved far from her home and became the school nurse for Seabury Hall, a newly formed Episcopal boarding school on the island of Maui. During her tenure, Snooker furthered her nursing education, becoming the first Nurse Practitioner in the state of Hawaii. Although she was intelligent and dedicated, Snooker was most known for her vibrant and unique personality.

Bettyann (Hamilton) Hazell began having epileptic seizures when she was seventeen years old. Diagnosed during the 1950s, Betty began a battle against her disease and social perceptions of epilepsy. After learning to recognize and control her disease, Betty became a nurse. In an era that encouraged women to become housewives, Betty built her career as well as a family. Rising through male-dominated hospital administrations, she reached the highest levels of hospital management. In her sixties, Betty challenged a hospital corporation’s age discrimination and won. She continued to work twelve hour days into her seventies, hired for her last position at the age of seventy-four.

Melissa Patterson struggled with an extremely rare form of cancer Chordoma. Chordoma is a little understood cancer. It is relentless and fatal. A young mother at the time of her diagnosis, Melissa fought to survive and raise her son, Christopher. She became her own advocate, using creativity and open-mindedness to seek out alternative cures and treatments. Melissa did everything on her own terms and never gave up hope. Her indomitable will helped her remain active nearly two years past the average survival term of her cancer.

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TABLE OF CONTENTS

INTRODUCTION	5
SNOOKER	8
BETTY ANN	40
MELISSA	75
CONCLUSION	102
APPENDIX	104

INTRODUCTION

This project is a labor of love. It began through horrible misfortune during my semesters at Mount Holyoke College and was inspired by the notion of uncommon women found so often on campus. My life has been shaped by exceptional women, and I see new examples almost daily, but this is also a project of grief and appreciation. It is a product of chance, culminating with the discovery of a random photograph of the three most important women in my life taken at my son's high school graduation, the only picture of these three women together. This is my attempt to honor them for their many gifts.

When I first envisioned this project, it was as a memoir, conceived through the desire to chronicle my experiences and explain the significance of these three women. But much of what made them so exemplary rested in what they offered to all who knew them; my perceptions were just one snapshot in a large album. These are not my stories.

Yet, in a way, they are; I am the writer and it fell upon my shoulders to choose how to convey their qualities and illustrate who these women were; I am their connection to the reader and I am the commonality where their lives intersect. By placing myself as a character of the narratives and using a third-person perspective, I gained a new understanding of who they were and my relationships with them. Although challenging, especially in the case of my

mother, the distance allowed the key aspects of character to shine; the space held back the personal and emotional reactions that would drive a memoir and color the reader's view. My perceptions and interpretations, however, still lie within each narrative.

As Annie Dillard claimed in *Inventing the Truth, The Art and Craft of Memoir*, "The writer of any work, and particularly any nonfiction work, must decide two crucial points: what to put in and what to leave out." I sifted through interviews, memories, and research materials, picking those events and information that could provide a stranger an accurate portrait of their characters, I had to find a balance between medical facts and indomitable personalities; disease was a major player in two of the profiles, but as in their lives, I could not allow it overshadow personality.

An additional challenge revolved around the voice of each profile. I sought to tailor the writing styles, sentence structures, and word choices to reflect each woman's personality. Melissa's struggle was a constant back-and-forth between living her life and combating her disease. The amount of knowledge she accrued regarding Chordoma was staggering. My mother was always moving forward, rarely looking back to the past, except in the case of her epilepsy, which simmered beneath her tough surface. Snooker was the most difficult to portray; she frequently hid her true colors behind her flamboyant persona, but that caricature was, paradoxically, as integral to who she was as her multitude of possessions.

Through this project, through the distance I chose to enforce, my intimacy with these women increased. They were integral pieces of my life, but through research and interviews, I discovered previously unknown facts and gained a more thorough familiarity with the strengths I admired. Glimpses into Melissa's childhood highlighted her indomitable will and unique view of the world. In the cases of my mother and my aunt, family myths were debunked and the realities of their shared yet separate childhoods became clearer. Difficult truths made their individual successes infinitely more potent, adding more detail, giving me the opportunity to view my friend, my mother, and my aunt through the eyes of others who knew and loved them; I saw them with new eyes. I heard new stories and found the same threads, reinforcing those intrinsic inspirational qualities.

It is impossible to know someone completely. Our perceptions of those we love or admire are limited in point of view and opportunity; our perceptions are like photographs freezing a memory. We know a version of the person, filtered through relationship and experience. What I have tried to do is create a panorama of these women, to show them through time and from many angles.

SNOOKER

Everyone knew her as “Snooker.”

The origins of the nickname were shrouded in mystery, but “Snooker” was an integral part of her being. Born on December 1, 1939, she was christened Helen Marie Hamilton. If someone called out for Helen in a crowded room, she would be the last to respond.

Snooker developed an extremely close relationship with her father, Bill, who gave her a pet name because he hated the name his wife chose for their youngest. Some relatives claimed that Bill began calling his second daughter “Snooker” in tribute to the type of billiards he played at South Philadelphia’s Gilligan’s Tavern, but most likely, he derived the moniker from either a comic book character popular in the early 1900’s named “Baby Snookums,” or a popular radio personality called Baby Snooks. Baby Snooks was created by Fanny Brice, the “Funny Girl” of the *Ziegfeld Follies* and by 1940 she was a regular character on the popular radio show, *Maxwell House Coffee Time*. The Hamilton family were avid listeners and Bill always provided the family with the latest in radio technology; a crystal set radio was one of his most prized possessions.

Baby Snooks was a mischievous young girl, first developed by Brice in vaudeville in 1912. The many radio skits and later television performances depicted her inquisitive and persistent nature. According to Gerald Nachman in

Raised on Radio, “The character may have seemed a noisy one-joke idea based on Snooks driving Daddy to a screaming fit. Yet Brice was wonderfully adept at giving voice to her irritating moppet without making Snooks obnoxious.”

Although Baby Snooks was a caricature of a pesky toddler, Snooker embodied the strong-willed and curious little girl; the comparison was evident.

As a child, Snooker was active and eagerly followed in the footsteps of her older sister, Betty. Although the sisters shared many interests and activities, the seven years between them allowed Snooker to solidify her own identity. Like her older sister, Snooker was an athlete, playing field hockey and tennis as well as maintaining excellent grades.

In high school Snooker was popular and confident, her friendships crossed the invisible lines of adolescent cliques. She was in the Honor Society, played basketball and was captain of both the field hockey and tennis teams. She was ranked number one in the school district for girl’s singles tennis. Though unable to carry a tune, Snooker sang in the chorus. Tone-deafness was no impediment if it was something Snooker wanted to do, she did it. Many in the high school remarked that Snooker did not date. Rumors began that Snooker was gay, like some of her female athlete friends. Snooker never paid heed to the rumors, preferring platonic relationships to romantic entanglements. Despite her datelessness, she was the head of the Prom committee.

Through the years, Snooker developed her unique sense of style. When she took possession of her older sister’s 1932 Ford convertible, Snooker bought a

crimson and black striped jacket to match the car's red paint. Although Betty won drag races with the car, Snooker would don her driving jacket and a Balmoral hat to match and drove at a leisurely speed around the neighborhood. The large red pom-pom bouncing from the top of the scarlet Scottish cap caught the wind as Snooker cruised the streets; she wanted everyone to notice.

After high school, Snooker continued with her tennis career and according to the Middle States tennis rankings was ranked fourth among teen players. She reached sixteenth place in the national amateur ranks. Snooker practiced, taught and competed at the Philadelphia Cricket Club. The Club's elite status and wealthy patronage impressed Snooker; she was drawn to the manners and culture of the rich. Blonde, blue-eyed, attractive, and outgoing, Snooker made friends easily and the Cricket Club provided her a forum in which to cultivate friendships with people she respected. Though Snooker tried to "know" everyone she met, she chose her close friends carefully, meticulously maintaining these relationships through many years. Her bulging address book chronicled the birthdays, family members, up-to-date contact information, and any significant dates. Years of penciled-in details and erasures smudged every line and added pages spilled from between the pages. With this continually updated information, Snooker made sure to acknowledge each friend on every holiday either by phone call, card, or gift.

Tennis was a vocation for Snooker, but it was not her career. Betty claimed Snooker lacked the discipline to evolve into a professional player. Snooker asserted a desire to enjoy the game, not force herself to play for fame and

money. Rather than sacrifice her pleasure in tennis, Snooker chose a profession. Like her sister Betty, Snooker was accepted at St. Joseph's Nursing School and in her years of study, Snooker excelled. She graduated first in operating room skills and at the top of the graduating class. After receiving her degree as a Registered Nurse, Snooker went to work at Chestnut Hill Hospital, the same hospital where Betty worked.

After two years of there, however, Snooker made a costly mistake involving a breach of hospital policy and an influential patient. The disciplinary action was kept from public record, but the grievance resulted in Snooker's appearance before the Pennsylvania Nursing Board. The hospital's complaint was upheld and Snooker's nursing license was revoked. She was no longer able to practice her profession in the state where she had lived all her life. Snooker was mortified. To escape her shame, she fled, relocating as far from her home as possible. Snooker moved to Hawaii.

Her first job in Hawaii was as a nanny to a wealthy family on the island of Oahu. The job supported Snooker long enough to gain familiarity with the island state while she applied for a Hawaii Nursing License. Once Snooker received her certification, she took a position at the Straub Clinic in Honolulu, assisting the staff cardiologist. Founded in 1921 by German educated Dr. George Straub, the clinic, according to its website, evolved from "the idea of forming a group of physicians to provide better, more specialized care for his patients." In this environment, Snooker reintegrated herself into a nursing community and began to

enjoy living in paradise. Through tennis, Snooker met Gertrude Berger; the two formed a life-long friendship. Snooker stayed with Gertrude's daughter, Stephanie, whenever Gertrude and her husband travelled. It was during this period that Snooker was involved in her only serious relationship.

Since she was extremely protective of her personal life, hardly anyone was aware of Snooker's romance. Her sister was one of the few people to whom Snooker confided, but Betty kept her sister's secrets. Betty only ever divulged a vague outline of a failed relationship. She told her daughter Nancie, "Snooker was engaged once. He was supposedly from a wealthy, prominent family, but they disapproved of the relationship." Betty's oldest daughter Anne remembered hearing, "He was brother to a powerful Episcopal Bishop, or something like that, but I don't know who." Gertrude Berger, who knew Snooker's beau, but forgot his name, recalled, "Stephanie was going to St. Andrew's and I think that is how he and Snooker met. They had an odd friendship. They were intellectually matched, however, he was a typical bachelor, in that he wasn't very neat. Snooker was always so put together and he was a bit sloppy, his clothes were always wrinkled or stained. I think he began to get on her nerves." She moved to Maui as the relationship was ending.

In 1966, Snooker left Oahu and joined the staff of Seabury Hall, a newly established Episcopal boarding school. The campus was nestled in "Upcountry Maui" a mile above Makawao town on the slopes of Haleakala crater, also known as the "House of the Sun," one of the largest extinct volcanic craters on earth.

Seabury Hall's grounds provided breathtaking views of the mountains and coastline of the island from its secluded vantage point. Snooker was hired as the school nurse and, when she arrived on Maui, did not look much older than the students. Her bright blonde hair, blue eyes, slim, athletic build, and wide smile made Snooker appear as innocently fresh-faced as an adolescent.

Seabury Hall began with a small community of educators and students and Snooker was an integral part of this "family;" she became fixture of the school. Fred Rawe, one of the first teachers at the school, described Snooker's arrival. "Snooker first strode across the cattle guard and onto campus with little more than a tennis racket, a Clara Barton do-it-yourself nursing kit, and a tenacious determination to instill her keen sense of community into this fledgling boarding school."

Snooker took up residence in Seabury's infirmary, soon making the rooms undeniably her own. Her biological family visited as often as time and money would allow, once or twice every few years, forcing Snooker to forge new connections. With her typical verve, she made new friends and contributed to the school community beyond the demands of her nursing position. The next addition to Seabury Hall after Snooker's arrival was a tennis court.

In the tropical setting, Snooker continued to play tennis year-round on the new Seabury court and at the Maui Country Club. She would play anyone, anytime Most of her tennis partners were male as Snooker's strokes were too powerful for the women she played against, forcing her to "pat the ball around the

court.” In one island-wide coed tournament, Snooker not only made it to the final, she trounced the male competition.

As she settled into her duties, Snooker found her true calling. At Seabury, she was part nurse, part den mother, photographer, tennis coach, and student advisor. The infirmary was set up in the middle of the dormitory and she was on call every minute of every day to the ninety boarders. When needed, Snooker would rush students to Maui Medical center; she was willing to drive students to checkups and orthodontist appointments at a moment’s notice, and she was frequently the provider of late night advice and snacks. According to faculty member Charlotte Melrose, “every boarding school should have a Snooker.”

As a permanent dorm mother, Snooker related well to her charges. She was a mother figure to the students, able to pick out the homesick and comfort them, while keeping a watchful eye over those who broke the rules. One Seabury graduate remembered: “One night I snuck into someone’s dorm room to spend the night. I wasn’t on the roster, and when Snooker came around for lights out, I dove under the bed. She opened the door and looked in and said, ‘Sarah Bott, does your mother know you’re here?’ Snooker never missed a thing.”

Snooker’s persona was her hallmark. The first indication that you had entered the presence of a singular individual was her voice, a nasal tone that was difficult to describe and impossible to imitate. It was half Saturday Night Live’s Church Lady, half Lily Tomlin’s character Edith Ann, lilting and childish, almost whiny. And according to Seabury alum, Icer Vaughan, “the dorm could always

hear her calling for her cat. Or rather the whole campus heard her, because it carried so well.” One Seabury compatriot described it as “a nasal drawl that’s drawn out to the winsome yowl of a lovesick cat.”

When she telephoned her nieces, before they could utter a greeting they were treated to an ascending, “Yes?” This was quickly followed by a staccato, “this is your Aunt-tie Snooker.” On one of her infrequent visits, Snooker entered Betty’s kitchen on an evening when Betty’s youngest daughter had invited her first boyfriend to dinner. Snooker burst into the room by saying, “Hello, I’m Snooker, the eighth wonder of the world! I’m sure you’ve heard of me. Or been warned!” She proceeded to describe how she had been friends with the young man’s great aunt and, in fact, for reasons unknown, had the high school hockey uniform of his relative. “I should get that to your mother some time, so she can return it to Mary,” was Snooker’s parting comment.

When she was away from the school, Snooker prided herself on her wardrobe. Adorned in classic suits or sophisticated separates with her hair curled and styled, Snooker always looked “put together.” Her favorite staples were button-down shirts and colorful vests. On days when her hair was less than perfect or when her platinum color was showing darker roots, Snooker wore hats. She had an extensive collection, including straw hats with flowers decorating the brim, tweed newsboy hats, felt hats, berets, and even a vintage top hat, but no baseball caps. Snooker could turn off her eccentric side without losing her

essence, but she had unwritten rules governing behavior and attire that only she understood.

At Seabury Hall, Snooker's work and home blended. The infirmary became both medical center and Snooker's world. Because she was on call every moment and rarely needed to leave her environs, Snooker rarely exercised her fashion sense, or rather, she followed different rules of attire. Her favorite outfit was a full-length flannel nightgown. Melissa Colflesh, the wife of the school headmaster and mother of a Seabury student, commented, "It took a long time for my daughter to realize that not everyone walked around all day in a nightgown." And since she was an expert seamstress, most were homemade. Snooker would order one "designer" nightgown and use it as a prototype, copying the pattern and replicating the design. Her favorite was Lanz of Salzburg. When she found a place where she could order bolts of the Lanz flannel, Snooker ordered yards and yards of the patterned fabric. Every Christmas, Snooker's female friends and relatives would receive a nightgown sewn from the latest pattern.

To store all of her flannel and fabric for her other sewing projects, Snooker delegated one of the infirmary rooms as her sewing room. In addition to nightgowns, she would sew dresses and Hawaiian muumuus, decorative pillows, quilts, duvet covers, wall hangings, Christmas ornaments, and placemats. She organized her vast collection of fabrics on a growing assortment of shelves and bins. Friends of Snooker could always count on a gift of a personalized towel, huge bath towels adorned with white cotton letters spelling out the recipient's

name or nickname. The towels were always the largest, softest terry Snooker could find. She spent hours in stores feeling every towel, buying as many as possible she discovered acceptable items.

The sewing room was soon joined by the Christmas room. Snooker had always been captivated by the Christmas season. She embraced the childish joy of giving and receiving gifts, singing carols, and putting up decorations. Each year, her artificial tree would be assembled earlier and dismantled later. Finally, Snooker left the tree decorated year round. Icer Vaughan, who lived with Snooker during his school years noted “it was always Christmas, all the time.” With a perpetual Christmas tree in residence, when the holiday season began, Snooker would set up a second tree and sometimes a third. And the trees were overwhelmed by her vast collection of ornaments and lights. Her discovery of lights that played music and strands with programmable flashing patterns was a monumental occasion.

Snooker would create wreaths and miniature trees for the dorm rooms, spreading the Christmas cheer. The two-foot trees were crafted with a theme, customized for the recipient. Snooker gifted trees festooned with miniature whisks, spoons, forks, and measuring cups to culinary friends. For gardening aficionados, the tiny boughs were buried beneath small-scaled trowels, gloves, shears, and hoes. Snooker was a marvel at finding unique miniatures to use on her trees. Any trip off the island presented an opportunity to find new and varied decorations for her Christmas creations.

Any space Snooker could decorate bore her artistic signature. The infirmary was festooned with garlands and lights. Santa figurines adorned every available space. Whoever was chosen to imitate St Nick at the Seabury Hall Holiday party knew that Snooker, most likely dressed in her elf costume, would be one of the first to sit upon his knee with her wish list. For the Seabury Hall community, Snooker was Christmas.

Despite her eccentricities, Snooker remained a consummate professional and kept pace with changes in nursing. In 1978 she was granted a year's sabbatical to further her nursing education. After extensively researching programs and options, Snooker was admitted to the Nurse Practitioner program at the University of Colorado Denver. Dr. Hanlon, the school physician supported Snooker's decision, he respected her abilities and implicitly trusted her judgment. For him, the NP degree was a mere formality; it was a chance for Snooker's education to reflect her knowledge.

The University of Colorado Denver, as noted in the College of Nursing information, was the "birth place of the 'Nurse Practitioner Movement.'" Snooker believed that the Nurse Practitioner program developed nurses capable of filling a vital role in the health professions. The nurses in the University of Colorado's program were pioneers in this brand-new field. By completing the program, Snooker received the equivalent to a Master's Degree in Nursing. She became the first Nurse Practitioner in the State of Hawaii, a milestone Snooker downplayed. Her family in Pennsylvania was completely unaware of that

particular honor. Before her return to Maui, Snooker's niece flew to Colorado. The pair drove Snooker's cherished Ford Maverick across Colorado, Arizona, and California. With Nancie reading the maps, they visited the Grand Canyon, Mesa Verde National Park, Sea World, San Diego Zoo and Wild Animal Park, and, of course, Disneyland. Snooker's sister, Betty, remarked, "I'm not surprised they had so much fun. They were mentally about the same age. It was a miracle they made it to L.A." When they reached Los Angeles, Snooker loaded her car onto a ship for transport to Hawaii, Nancie flew back to Pennsylvania, and Snooker boarded her own flight to return to Seabury Hall.

With her new certification, according to the UCSF Center for the Health Professions, Snooker now had the "explicit authority" to diagnose, order tests, and refer a patient to a specialist or other physician. She could also prescribe medications, including controlled substances, with the involvement of a Medical Doctor. But her medical prowess never overshadowed her involvement with the students or her personality.

By the middle of the 1980s, the school was changing. The number of day students was increasing and the costs involved in running a boarding program were skyrocketing. Snooker was kept on staff as nurse, but her duties reduced. She remained an excellent health care provider. Maria Rawe, Snooker's closest friend asserted, "Snooker kept up with the latest in nursing innovations and practices through a national nursing magazine subscription. I always admired her for being able to keep in touch with the latest happening...and although she did

watch a lot of TV, she also read an immense amount.” In addition to applying her knowledge, Snooker relied on her excellent instincts. According to Dr. Deborah Mathias, “Snooker was always up to date on the latest vaccination protocols and always knew the appropriate testing. She was more thorough than any doctor and her scoliosis checks were second to none.” It helped that Snooker always treated the students as people, though she was not a pushover. She could spot a faker a mile away. She usually knew what assignments were due from which teachers and would gauge infirmary visits accordingly. During finals, she remarked, “it’s amazing how many students are suddenly dying from mysterious diseases.” Many boarders who visited the infirmary were treated with some aspirin or a band-aid and sent back to class.

Her maxims for health stuck with the students and her friends. Maria recalled: “If I had a particularly bad cold Snooker would tell me, ‘Well, Maria, you can take your medicine and it’ll go away in seven days, but if you don’t, it’ll take a week.’” But Snooker was sensitive to those who genuinely suffered, frequently driving them to the hospital, advocating for them to be sure they received proper medical care, and injecting a combination of caring and comedy to otherwise traumatic situations.

As the years passed, many of the teachers who had participated in the building of the school moved away. Maria and her husband Fred, two of Snooker’s dearest friends, moved to Atlanta. Snooker moved into their old house, quickly spreading her collections and crafts throughout the small bungalow. As

the community moved into the future, Snooker straddled the present and the past. She reveled in Seabury's history, becoming the school archivist. When alumni events were planned, Snooker played a pivotal role; she was the one who remembered the alumni, knew where they had headed after graduation, and cultivated lists of their spouses and children. When event time arrived, Snooker worked tirelessly to turn the campus into a decorated wonder.

In the bright sunshine of early July, music blared. John Philip Sousa's *Stars and Stripes Forever* blasted into the tropical heat from speakers placed in the windows of Snooker's house, reminding everyone of the nation's birthday. A huge flag undulated in the warm breeze, while a multitude of smaller cousins poked from window boxes and the borders of the garden. Snooker woke early, enjoyed her customary breakfast of Coca-Cola Classic and Sturgis pretzels, consulted her encyclopedic T.V. schedule, followed her copious notes, and set the V.C.R. to record the finals of the Wimbledon tennis tournament. The handwritten television instructions were provided by Icer Vaughan, the Seabury student who was Snooker's electronics guru and an integral piece of Snooker's life.

Her ability to pick up the attitudes, needs, and talents of her charges brought Icer and Snooker together. A shared interest in photography formed the basis for their relationship. Snooker had taken her first photo at nine-years old, a photo she kept along with every other she took. "She taught me everything I knew about my way around a dark room," Icer remembered. Snooker recognized the difficulty Icer encountered as he tried to find his place in the student population.

According to Snooker, “he just needed encouragement, someone who could appreciate and support his talents. He was so shy. But he was a whiz with computers and the satellite dish!” Icer helped install a large satellite dish which had to be programmed to locate individual satellites and coordinate with certain channels. The receiver was wired to various recording devices, as Snooker needed to be able to record her favorite programs while watching another. It was a complex system and Snooker was electronically illiterate. To run her state of the art system required a notebook full of channels, corresponding satellite locations, and detailed instructions, including how to turn on the system step-by-step. Once the dish was up and running, the faculty and students would gather at Snooker’s house, making reservations for favorite shows or televised sports, and crowding into the cluttered rooms to watch.

Icer lived with Snooker from the time he matriculated at the age of thirteen until his graduation day in 1991. His shy demeanor complemented Snooker’s outrageousness. For Icer, Snooker became a mother figure and he became the son she never bore. Even when Icer returned to the mainland for college, they retained their bond. Icer was always closest to Snooker’s heart.

By 1996, Seabury was strictly a day school. The swimming pool was replaced by a new field house, the dormitories torn down to make room for more classrooms. The original building had tripled in size. Snooker’s house was one of the few remaining staff bungalows. The school made the decision to cut out the position of resident nurse. After thirty years in that role, Snooker retired. The

event was marked by a *Maui News* article, “Seabury Hall is losing its nurse and a part of its history.” The text, nearly half of the front page, was accompanied by a large color picture of Snooker, wearing a white t-shirt beneath a madras plaid jumper, leaning on a porch railing surrounded by her collection of potted ferns and tropical plants. It was a difficult move, but Snooker packed up her collections of fabric, craft supplies, Hawaiiana, holiday decorations, three sewing machines, and her Honda Prelude for a move to New England.

In Vermont, Snooker moved to a small farm owned by her sister Betty, complete with a barn, three horses, and a goat. The image of Snooker caretaking equines was hilariously ironic to her Maui friends because the one event Snooker loathed at Seabury Hall was the student “breakfast ride.” Snooker would stand as far from the animals as possible, muttering, “nice horsey.” Also, the farm in Vermont and the horses were indirectly instigated by Snooker. Betty’s daughter Nancie first took riding lessons during a visit to Maui in 1977, when Nancie expected to learn to play tennis during a summer-long stay. Unfortunately, a few hours after Nancie’s arrival, on the way to the school swimming pool, Snooker stepped in a hole and shattered her ankle. To keep her niece occupied during the visit, Snooker arranged riding lessons. Nancie’s love of horses never waned and Betty’s ambition to own a farm coalesced in Vermont as Winterwind Farm, Snooker’s new home.

Snooker discovered she enjoyed mucking stalls, and learned to love the animals. The goat was her personal favorite. George D. Goat was adopted as a

Mother's Day present for Betty from Nancie. He was large—nearly three feet tall at the shoulder—with foot-long horns arcing from the top of his head. George was playful, rearing onto his hind legs and bouncing toward an unsuspecting person whenever he felt frisky. Though he usually halted a few feet away, he was intimidating. Snooker carried a plastic pitchfork as a prod whenever he got too close. “He’s the perfect height to puncture your descending aorta,” she frequently lamented. But she developed a bond with George. “Show me your chicklets,” she would tell him, referring to his bottom row of tiny teeth which he revealed on command.

Vermont offered other challenges. After three decades in a tropical climate, Snooker had to adjust to seasons. Snow was a novelty. Every snowfall was recorded and each snow-day was like Christmas morning; she would excitedly call her friends to report the amount that had fallen. Bundled up in one of her long, down L.L. Bean coats, wool pants, Muck boots, a hat, scarf, and two pairs of gloves, Snooker would head outside with her camera to take pictures of the snow on the trees, the horses frolicking in the white powder, or the deer hiding beneath the pine trees. Although she loved the look of fresh snow, she refused to drive in it; her car, sporting a new green and white Vermont plate, MAUI 1, was parked in the aisle of the barn, protected from the icy precipitation.

The town of Chester became Snooker's new community. Her outgoing personality and persistence guaranteed Snooker a place as a civic fixture. She joined a quilting group. When the weather warmed, Snooker found a tennis group.

Substitute teaching brought in extra money, as did helping part-time at the local bookstore, and she regularly house-sat for her new acquaintances. She was often found in R.B. Erskine's feed store talking to the owner and patrons or across the street at Lisai's market catching up on town gossip. Within months, Snooker knew more about the town and its residents than many of the natives. Her encyclopedic mind catalogued who was married to whom, their children, where they lived, where they had moved from, occupations, scholastic achievements, and what kind of car they drove.

During the summers, Snooker explored the area. She would drive hours to visit sites she had been told about or that she had seen advertised. She discovered the best thrift stores, where she added to her huge collection of coats and button-down shirts. Following sales flyers, Snooker would search out bargains. On any given week, she knew which store had the best price on diet soda and ice cream. If there was a craft fair within a three-state radius, Snooker knew not only when and where, but which vendors would be attending. Hours were lost in discount stores. Snooker was always on the lookout for new storage solutions, craft ideas, and gift possibilities.

In 1998, Nancie took over the farm and Snooker rented an apartment on Chester's main street. The rental consisted of the top floor of a converted farmhouse and included a large basement as well as a garage. Snooker filled every inch of the space.

Snooker typically used the back entrance to the apartment. From the second floor porch, which overlooked the back lawn, a door opened into Snooker's cluttered kitchen. A large hutch displaying an impressive collection of pewter dinnerware and an oak drop-leaf table crowded the space. Every flat surface was buried beneath magazines, newspapers, and post-it notes. Colorful pieces of paper and fabric mingled at the foot of decorative bowls and vases, which were filled with fake flowers, real fruit, or ornamental ceramic balls. Tins of freshly-baked cookies filled the air with sugary aromas. Each tin contained a different type of cookie and pieces of stale bread. Snooker claimed the bread kept the cookies soft and chewy. Plant clippings floated in blue and green glass vases on every window sill and rooted cuttings sprouted from hanging baskets. Every year Snooker would fill planters outside with coleus and geraniums and each fall she would not have the heart to throw the annuals away. She brought them inside and used the new plants in gift-baskets.

A narrow hallway began with floor to ceiling shelves and a decorative arch. Larry Carbonetti, landlord, retired English teacher, and carpenter built the divider to provide Snooker with much-needed display space. The shelves held valuable treasures—such as an intricately carved ivory sphere, its multiple layers only observed when held close—nestled between dollar-store wooden ducks. Hiding behind the shelves was a Christmas tree, festooned with the ornaments that held special meaning for Snooker. Boxes for gifts she intended to send lined the floor.

Every wall was covered with Snooker's collection of art and photography. Large watercolors by Snooker's friends, such as Maui artist Sherri Reeve, Jeanne Carbonetti and Vermont acquaintance Irina Ohls, were scattered between photographs Snooker had taken in Hawaii or while chaperoning a Seabury Hall trip to Europe. Each piece was meticulously matted and framed, most by Snooker herself. During the time when photography was one of her primary passions, Snooker bought countless cameras, would develop her own pictures, cut mats on her professional mat-cutter, and fit them into frames. In Vermont, the cameras and lenses were hidden in a bureau drawer and the closet. She bought a small digital camera after extensive research as to which brand and model would suit her needs.

In Snooker's small bedroom, a twin bed, a large bureau and mirror, two cedar chests, a night-stand, and a bookshelf competed for floor space. The walls were covered with curio shelves holding cloisonné ginger jars, china cups, and miniature models of cars. Strands of shell leis dangled from hooks.

Snooker had collections of jewelry stowed in boxes and drawers. Visits to craft fairs in Hawaii and New England provided Snooker with samples of the works of varied artisans. Handmade pins and earrings, still on sale cards, filled the top drawer of her bureau. Satin boxes and silk jewelry bags protected Snooker's most cherished pieces. Kilt pins—for Snooker's collection of tartan skirts—and a brooch with the Hamilton crest littered a wooden tray. The tray was crafted from koa, a rare form of acacia native to the Hawaiian islands; before colonization, koa

was reserved for the Hawaiian kings. Throughout Snooker's apartment koa pieces mingled with wood bowls and platters made of monkey-wood. Monkey-wood was a more common, cheaper material, almost indistinguishable from koa. The mix of expensive pieces and cheap knockoffs continued through the apartment. But their owner knew the value of every specimen.

The living room boasted a second hutch, an oriental storage table, a classic colonial blue couch, an antique French lingerie chest she "borrowed" from Seabury Hall, shelves displaying pewter pieces, and her large Sony Wega television hooked up to both cable and satellite reception. Snooker needed access to local channels as well as the variety that satellite reception offered. The coffee table displayed a month's worth of Vanity Fair, Time, Newsweek, TV Guide, and Orbit magazines. Pairs of reading glasses in red, black and purple littered the surface. Notes to remind her how and when to set the VCR to record specific programs were stuck to the fronts of the magazines and the edges of the TV. VCR cassettes filled shelves, their spines revealing the details of the contents and the date they were created.

The apartment's second bedroom was devoted to sewing, card making, and rubber stamps. A collection of new books reserved for gift baskets were crammed into a low bookcase. At any moment, Snooker could provide a book on anything from cooking to cats. File cabinets full of greeting cards organized by holiday and age group as well as personal records and important documents, (including the script for her answering machine greetings) served as legs for a six-

foot plywood desktop. On top sat bins of ink-pads for the rubber stamps, an answering machine, and the computer Icer sent. Post-it notes papered every surface reminding Snooker of appointments, birthdays, addresses, phone numbers, recipes, websites, and any trivia she felt was necessary.

The second hallway sported steps leading to a front door; the banister was wound with garlands of artificial pine and multi-colored lights. Shelves and baskets led the way to a lonely third bedroom reserved as a guest room. The comforters on the twin beds were rotated according to season, but they were only visible when company was expected. Otherwise, they were used as places to sort gift items or clothing. It was a mystery where she hid her mess when she had visitors. The space under the beds was already cramped.

Downstairs a small foyer and narrow hall led to the basement steps. Coat racks staggered under the weight of too many coats. A red gypsy cart full of Easter and Halloween candy snuggled next to a heavy antique oak desk that served as storage for unburned candles. The wall in the front hall held two large white and red Hawaiian quilts, given to Snooker at her retirement ceremony. Each floral inspired design measured two feet by two feet and scalloped with an intricate quilted pattern. The simple wood frames were custom crafted from the finest koa. In the sewing room a number of imitations in bright yellows and greens were stacked as they waited to be made into decorative pillows.

Snooker's basement was part storage and part craft studio. Industrial shelving lined one and a half walls, the shelves crammed with plastic storage

containers and memorabilia. Snooker saved old license plates, and telephones. Pete the Repeat Parrot sat in a box, ready to be sent to whoever Snooker decided deserved to have their words recorded and repeated. Trunks of fabric and clothing stacked four high and four deep encompassed the center of the floor. Fabric wardrobes lined two walls. One was filled with coats, another with Hawaiian shirts, muumuus, and Christmas costumes. The others held contemporary clothing that Snooker rotated upstairs according to season. A large workbench drowned beneath chaotic piles of ribbon, pine cones, leaves, glitter, miniatures and miscellaneous art and craft supplies. Plastic flowers and strands of raffia grew from beneath its surface. Baskets dangled from every beam, crowded on hooks like straw grapes on overburdened vines. A large hopper of tennis balls hid beneath the steps.

Everything in Snooker's home had a purpose. She avidly followed every holiday and made sure she was prepared for each. For Halloween, Snooker had a large steamer trunk full of possible costumes. On Maui, she lent these to students and faculty. In Vermont, they fell into disuse, though she strongly encouraged her friends to dress up. If she could not don a costume, Snooker settled for wearing decorative headbands adorned with pumpkins or bats. Her favorites lit up, made noise, or both. Although Snooker loved to acknowledge every holiday with a card or note to her friends in Hawaii, her sentiments rarely arrived on time. A Halloween card sent to Charlotte Melrose was dated November 16. Inside Snooker wrote: "Do you really think I can look beyond the pretty calendar

pictures and ever notice there are numbers and blocks? Too much for my cluttered mind.”

“You’ve reached Peter Rabbit radio, home of Snooker, O Wonderful one, reminding you it’s the season of maple syrup, spring bulbs, and my favorite, chocolate bunnies. Leave me a message and I’ll call you back. I hope you have a wonderful day.” Snooker’s answering machine always reflected the season. At Easter, Snooker would create special baskets dripping with colored plastic grass, jams and jellies made the previous winter, small stuffed bunnies or chicks, and a box of either butter cream or coconut eggs from Bergen’s Chocolates of West Point, Pennsylvania. Bergen’s did not typically ship from their small, family chocolate shop, but for Snooker they did. The baskets were usually accompanied by a card Snooker crafted from intricately cut-and-glued paper.

Snooker enjoyed card making; she searched for ideas in Hallmark stores, gift shops, and book stores. When she found an idea she liked, she would create her own designs. For Easter, Snooker cut out tiny paper baskets and loaded them with paper eggs, grass, and bunnies. Summer cards sported origami Hawaiian shirts. There were cards with Christmas themes, birthday themes, and Oriental themes. Her growing rubber stamp collection allowed Snooker wider ranging designs. A local clothing store, where Snooker occasionally helped out, began to sell her creations, but she could not keep up with the demand; there were too many other projects requiring her time.

In the fall, Snooker would thaw berries she had picked during the summer. Every year she called local orchards and farms to check the status of their crops. She developed a rotation, strawberries from Wellwood Orchards, blueberries and raspberries came from the farms along the Connecticut River. In August and September it was back to Wellwood for peaches, apples, and pears. With her abundance of fruit, Snooker hunkered down during the dark evenings boiling and canning. The results of her labors, labeled and dated, were set aside for the Christmas baskets Snooker would send out to her many acquaintances.

Despite the chaos and her multitude of odd jobs, Snooker was hired as the school nurse at Vermont Academy. Her experience with boarding school populations and adolescent health care made Snooker a valuable member of the health services team. She quickly familiarized herself with the student population, applying her uncanny ability to understand them, making them feel like their concerns were important; she treated them with respect even when she ordered them back to class. Maryann McArdle, the dean of students at Vermont Academy, noted, “the students adored her. They all called her Snooker. At Vermont Academy everyone else is Mr. This or Mrs. That.”

Snooker continued to practice her nursing philosophy of “a band-aid and back to class” and of going above and beyond for those truly in need. On one occasion, a boy was injured while playing hockey. The game was one of the last before winter break. Most of the staff and student body had abandoned the campus for vacation. Snooker was on call in the health services department

preparing to leave for the night. An EMT examined the student and declared him unfit to play. The boy began to feel unwell and reported to the infirmary. Snooker suspected a concussion and, understanding the specific circumstances of a recent tragedy in the boy's family, notified his guardian, and drove him to meet his ride home. She called the following day to check on the boy's condition.

But the summer was Snooker's most active season. Her answering machine declared, "John Phillip Sousa radio," and reminded the caller to celebrate "Memorial Day and the poppies at Flanders Field." She loved the band concerts that many of the small towns arranged for warm evenings. If she could not find a friend to accompany her, Snooker would go alone. Dressed in red, white, and blue, a straw hat with a flower lei around the brim, Snooker would carry her picnic basket—loaded with Diet Pepsi, some cheese and crackers, a blanket, and a chair—to the town green. She always had extra food she shared with her neighboring music enthusiasts. By the end of the program, Snooker would know the stranger's family history and have a new friend.

The two-month hiatus from work allowed her to focus on her projects. In the warm weather and long days, Snooker cultivated a garden. The owners of the apartment house, Jeanne and Larry Carbonetti, gave Snooker permission to design and plant flowers and vegetables. Larry rototilled a large circle in the sod. Every morning and late evenings, Snooker could be seen from the road in either her trademark Lanz nightgown or her bug suit. She had developed an uncomfortable allergy to the ubiquitous bugs known affectionately as "no-see-ums," so she mail-

ordered a mesh shirt and veil and stocked up on bug repellent. Creating a garden despite the bugs and the short growing season was a challenge. With her niece in tow, Snooker scoured garden centers and local nurseries to find the perfect plants. She consulted her numerous gardening books and carefully placed each specimen. A detailed diagram chronicled the garden. But every summer, despite her drawings and notes, she would call her niece over to identify what was coming up through the layers of leaf mulch.

Between her quilting group, the tennis ladies, and the garden, Snooker was always on the go. The Honda Prelude she had so carefully shipped to the mainland began to falter. When the time came to replace her vehicle, she bought a silver Ford Focus wagon. It became the new “MAUI 1.” She loaded the extra space with a basket full of bags, maps, plant catalogues, and an emergency 12-pack or two of Diet Pepsi. With a reliable vehicle, Snooker ventured farther from Chester. She visited Burlington, Vermont and old friends who had relocated to Fitzwilliam, New Hampshire. Bringing a decorated basket full of cloth napkins, quilted coasters, teas, chocolates, and maple syrup, Snooker reconnected with high-school friends in Pennsylvania. She encouraged everyone to visit her in Vermont.

Lynne Englebreath had known Snooker since the fifth grade. They kept a long-distance friendship through the many years Snooker lived in Hawaii. When Snooker moved to Vermont, Lynne was one of the first guests Snooker entertained. For three days the pair traipsed across the Vermont countryside and

stayed up late into the evenings. When it was time for Lynne to return to Pennsylvania, a friend who owned a Vermont summer home agreed to drive Lynne south. Lynne loaded her bags into the waiting car and gave Snooker a long hug. “Safe journey,” Snooker wished. It was a superstitious mantra she repeated whenever anyone left. Lynne eased into the passenger seat and the car pulled away. The driver turned to ask Lynne about the visit. Lynne held up her hand. “I have just spent three days with Snooker. Do me a favor. Don’t talk.”

This solitary, busy existence suited Snooker. Whenever she wanted company, she would arrange a tennis match or call a friend to accompany her on some well-planned outing. Her lifestyle also allowed Snooker the freedom to set her own hours. When she was not expected at work, Snooker would stay up half the night working on her craft projects. Though she lamented to Charlotte Melrose, “Despite my exhaustive research, I cannot stretch a twenty-four hour day into a thirty hour day,” Snooker certainly tried. Most nights, she squeezed a card table into the living room and pattered with her latest creation while watching one of the thousands of programs she recorded on the VCR. After mastering remote recording, Snooker would tape hours of craft shows, movies, figure skating, tennis, and the school board meetings from the public access channel. Snooker loved knowing the latest news in town.

In 2006, Snooker’s sister Betty moved to Chester. The residents who occupied the first-floor apartment were planning to move into a new house, allowing Betty to move in downstairs from her sister. While waiting for the old

tenants to leave, Betty took over Snooker's spare bedroom. It was crowded. Betty had two small, young dogs and a half-grown cat. Although Snooker had been known in Hawaii for her collection of felines, usually three at any given time, since moving to Vermont she had been petless. The animals knocked over Snooker's chaotic piles and they chewed the ornaments on the Christmas tree. Betty complained that there was no room for her clothes. Tensions rose.

By the end of April, the downstairs apartment became available. The Carbonetti's removed a partition, which allowed the sisters to share the entire house, but with separate bathrooms and kitchens. Even with the additional space, the sisters ate together and spent the evenings in front of the television.

In July, Snooker returned to Hawaii. On Maui, Snooker reconnected with her old life, spending time organizing a reunion. She house-sat for friends, moving from the Colflesh's house, to the Huff's, to the Haines residence, which included caring for their blind and deaf dachshund, Ziggy. Alyce Haines wrote, "I treasure the gifts she made for us and the mementos of her time with the dog." Even when house-sitting, Snooker would practice thoughtful generosity. Snooker noted the changes to the campus and the entire island. She missed the simplicity that had disappeared under progress and development. But being with the people she considered family made Snooker happiest.

At the celebration for her sister's seventy-fifth birthday, Snooker joined her nieces, Nancie and Anne, Anne's husband, Dave, and her sister Betty on the deck of a popular Brattleboro, Vermont bistro. As the appetizers were served,

Snooker took the orchid centerpiece from the table and placed it upon her head. She kept it there through the meal.

In late August, Snooker received tickets to the Pilot Penn Tennis Championships held in New Haven, Connecticut. She attended the first three days of matches alone. On Friday, August 25, Snooker convinced her sister to accompany her. Betty went to work for the morning. Snooker packed the car. In the early afternoon, the pair set off for New Haven, taking Snooker's Ford Focus instead of Betty's brand new Toyota Tundra.

They were on their way home when a twenty-one-year old drunk driver crashed into the back of the car.

Luis Medina was angry after a fight with his girlfriend, the mother of his two young children. Enraged and intoxicated, he wove in and out of traffic at speeds approaching 130 miles per hour. He flew by a construction site and a Connecticut State Trooper pulled out to flag down the white Nissan Maxima. The trooper was about to turn on his lights when he saw the flash.

Snooker's car was crushed by the impact; the back half of the car crumpled beneath the front seats making the wagon look like a sub compact. Luis' vehicle hit with such force from behind catapulting the silver Focus down the highway, the front airbags never deployed. A perfect imprint of the Maxima's license plate was embossed into the wreckage of Snooker's car. Two small cracks marred the windshield, but the front of the car appeared undamaged. Both women were killed almost instantly.

Luis walked out of the hospital the next day.

The coroner's report declared that Snooker died from multiple blunt force trauma. In his report the medical examiner noted, "The aorta is lacerated in the descending portion." George, the goat, had died the previous May.

Snooker was memorialized in three separate services, the first in Chester, Vermont. Although it was a celebration of the lives of two sisters, the majority of the mourners were there to commemorate Snooker. Following the service a small gathering was held in Snooker's garden. Friends from her quilting group and tennis partners provided refreshments as appreciation for the many gifts Snooker gave them through the years.

In Pennsylvania, the second service was attended by the many high-school friends with whom Snooker had kept in touch through continued correspondence. A reception was held at the Philadelphia Cricket Club, the site of many of Snooker's tennis accomplishments before her ashes were interred with her parents.

The final memorial occurred at Seabury Hall in December, an appropriate and touching gesture, one final goodbye at Christmas-time on the island Snooker loved. Because the chapel was too small to hold her admirers, it was moved to the new auditorium. Snooker's friends and the Seabury staff created a DVD entitled "Celebrating Snooker." In the memorial DVD, Lehn Huff wearing a headband shaped like a Christmas tree, described her last summer visit with Snooker. "She hadn't changed a bit. The best thing Snooker taught us was not to take ourselves

so seriously.” Paul Wood, a long-time friend, described her best: “I could never figure out if her traits were cultivated as some kind of comedy or if they were so intrinsic to her that she didn’t have any choice about it. Here was someone who would never be the same as anyone else and was really quite proud of that.” As the mourners filed out into the Maui sun, “Stars and Stripes Forever” blasted a final time across the Seabury campus.

Back in Vermont, the message on Snooker’s answering machine preserved her final seasonal greeting: “Welcome. This is Snooker, O Wonderful one, telling you to celebrate B. and B.: Bugs and Berries. Leave me a message, 875-1144, and I’ll return your call. Leave me a really good message and I’ll return it sooner. Have a wonderful day.”

BETTY ANN

The '48 Ford sedan cruised through the bright spring day. Four high school seniors were returning from celebrating their impending graduation. Tom Robinson drove. His girlfriend, Pam McMullin sat behind him, allowing her best friend, Betty Hamilton, to ride shotgun. Betty was prone to car-sickness, so Pam good-naturedly shared the back seat with Betty's beau, Tony Lukeman. Betty turned sideways and leaned against the door to talk to Pam. The car climbed a hill. Suddenly, Betty lost consciousness and pitched against the door-latch. It released. The passenger door flew open and Betty tumbled from the car. She landed on the hot pavement, her bare head bouncing on the tarmac as she tumbled down the road.

Betty Ann Hamilton was born on August 12, 1932. She was the first child for Henry William "Bill" Hamilton and his wife, Kathryn. Following a storybook romance, Bill and Kathryn had been married for nine years before the arrival of their first daughter. Despite defying their parents by eloping to Maryland and hiding their marriage for a year, Bill and Kathryn were not physically demonstrative beyond the conservative norms of the time. Kathryn once remarked, "It's amazing we had children at all." They brought their newborn home to their tiny row-house tucked on a quiet side street just beyond the Philadelphia city limits.

As the youngest of eleven siblings, Kathryn had little experience with infants. She was extremely superstitious and her biggest fear was losing her baby. She was afraid to touch the infant and limited her contact to essential tasks, such as feeding, bathing, and changing; no one else was permitted to hold little Betty. At night, Kathryn would sneak through the hole Bill cut in the wall that divided the closet of their bedroom and the nursery. Through the secret opening, Kathryn could watch and listen until assured Betty would keep breathing and survive until morning.

Although it was the height of the Great Depression, Bill earned a steady paycheck as a mechanic for the Ford Motor Company. He was an avid car enthusiast who began driving as soon as the first cars were available. At the time, there was no standardized motor vehicle operator's test. Bill was automatically issued a license; his first official driver's test was taken following his first fender-bender when he was seventy-years old.

Despite the lack of physical nurturing, Betty thrived. She was outgoing and vivacious, performing in plays with neighborhood children. When she was seven, Betty gained a sister, Helen. Betty nurtured her new sibling, frequently pulling her along the street in a wagon during the summers, or piling the toddler on her back when sledding in the winter. For Helen, "Betty was truly the best big sister anyone could have had."

Both girls were encouraged to be competent and competitive. Kathryn, the daughter of German immigrants, strictly enforced the rules at home. She made

sure her daughters were diligent in their school work, expecting nothing less than academic excellence and laziness was not tolerated. Kathryn demanded perfection.

When Betty learned to drive, her father presented her with a red 1932 Ford Roadster convertible. Bill's skill as a mechanic for Ford Motors blossomed into an interest in high performance engines and car racing. His personal cars were always "modified" to perform a bit better than the average family vehicle. Needless to say, Betty's car was fast.

A popular pastime for Betty's friends was drag racing along Bethlehem Pike, the town's main highway. The cars would line up to race from traffic light to traffic light, and Betty, who was raised to never consider herself inferior, would brazenly challenge the boys. Although she was tiny, barely five-foot-two and skinny, behind the wheel of her car Betty felt taller and stronger than all of the boys. She rarely lost.

In her junior year of high school, however, Betty began fainting. The first time her best friend Pam witnessed Betty passing out, they were posing for a photograph of National Honor Society members. "Betty was standing with us one minute, then she just fell straight forward onto the concrete floor." When Betty began having more frequent fainting spells, "we were very protective of her. We didn't know when it would happen; even Betty didn't know when it would hit her." Pam began noting a change in her friend, who "was popular and pretty, with

a great sense of humor. She was an exceptional athlete.” Betty played tennis and field hockey. “And she adored Tony.”

It was only following her fall from the car in her senior year that Betty was diagnosed, but by that time, the illness had already begun to take its toll. Her spells were so unpredictable, Betty was no longer able to compete in sports and she had trouble concentrating in school. She watched her friends make future plans as her own possibilities evaporated. Pam was planning her wedding. Tony was preparing to leave for Dartmouth College and a future without Betty. For him the illness and Betty’s fragility were too challenging for a long distance relationship; he dumped her.

An electroencephalogram, a test for measuring brain function, revealed an abnormality. Betty had epilepsy. Often referred to as a seizure disorder, the term epilepsy refers to a wide range of afflictions. From short petit mal losses of consciousness and fainting to grand mal events where the victim thrashes uncontrollably, both types, all lengths, severities, and causes fall under this same general classification. To be considered epileptic, a victim must have more than two episodes or seizures of any type. Betty’s seizures were typically a mild form of grand mal called complex partial seizures; she would faint or fall, lose consciousness for a few minutes, awake disoriented, and return quickly to normal.

Unfortunately, at the time of Betty’s diagnosis, the disease was horribly misunderstood by the public and the treatment options caused more damage than the symptoms. Outside of the medical sphere, epilepsy was viewed as a mental

disease and epileptics were considered insane. Even her younger sister refused to believe Betty had a treatable medical condition. Helen claimed her elder sibling “had a nervous breakdown because Tony Lukeman left her.”

In 1950, epilepsy was understood as a defect in the electrical processes of the brain, but the social and emotional effects were only beginning to be studied. William G. Lennox M.D. considered epilepsy a “double headed (medical social) problem of large proportions” in “Epilepsy—a Problem in Public Health.” The article, published in the May 1951 *American Journal of Public Health*, described the unrecognized challenges faced by epileptics and their families. He questioned the validity of the stigma applied to those who suffer from seizures. Lennox wrote: “Unlike persons with a visible physical disorder, the epileptic and his family carry the twin burdens of fear and secrecy.”

Betty’s mother succumbed to popular opinion. Kathryn felt it was a failure in her abilities as a mother or a punishment meted out upon her daughter; emotionally Kathryn alternated between loathing and disgust. Above all, Kathryn wanted to hide the unpleasantness of the disease. Her perfect child was irrevocably broken and the entire community knew why. Like so many in the 1950s, Kathryn shied away from the epileptic.

Pharmaceutically, research and development of new medications to control seizures were being introduced at the rate of one per year. As research and development continued, these new drugs began to take the place of Phenobarbital, a barbiturate frequently prescribed for seizures. Phenobarbital sedated and calmed

abnormal electrical impulses within the brain. The sedation, however, was significant, impairing the patient's ability to function, especially when engaging in tasks requiring high levels of concentration, such as driving a car. Newer drugs had fewer sedating effects, but carried additional side-effects such as poor concentration, nausea, personality changes, hyperactivity, increased or decreased libido, and insomnia. During the decade at least one new anticonvulsant per year was introduced. Of the new drugs marketed during the 1950s only two, Phenobarbital and Phenacemide are available today.

To find the right medication and dose, Betty was subjected to Electroshock therapy, a process inspired by the practice of electrocuting pigs prior to slaughter, which involves sending electrical current through the brain to induce a grand mal seizure. Electroshock therapy gained popularity as a tool for both seizure disorders and mental disease. It was made horrifically famous in the film *One Flew Over the Cuckoo's Nest*, but the treatment had largely fallen out of practice by the late 1960s. Today, Electroshock therapy is again used for severe depressive and bipolar disorders, but the amount and duration of exposure to electrical current have been drastically reduced; patients are also anesthetized for the duration of the procedure. According to Andy Behrman's website and book, *Electroboy*, "Patients in the 1950's sometimes received more than 100 treatments. The amount of electricity used was also greater, and the waveform and the stimulus were different."

For her treatments, Betty was strapped to a hospital gurney; her arms and ankles were secured to the side of the table with leather cuffs. Electrodes were attached to either side of her scalp and increasing levels of electric current pulsed through both lobes of her brain. When a seizure was induced, the amount of current was recorded on a chart. The information was used to evaluate the efficacy of the medicine and dose. The more effective the medication, the higher the current of electricity was needed to induce the seizure. Besides the horror of being restrained and then shocked, the procedure could also cause burns to the scalp, broken bones from the combination of seizure and restraint, acute or mild memory loss, and permanent brain damage.

The medications and treatments were destructive, but epilepsy was insidious. Betty had no idea when or where a seizure could strike, and while in the throes of an attack she was completely helpless. Everyday objects became threats: she could fall off a chair, her head could hit a counter-top, she could be writhing helpless in the middle of a street, or drown in her bathtub. The physical harm was as potent as the emotional embarrassment. Whether at home, in a car, strolling along neighborhood streets, in a classroom, or out to dinner, for Betty, the possibility of a seizure became an obsession.

The diagnosis destroyed any hopes Betty had for her future. Her dreams of a life with Tony or going to college died. She had planned to matriculate at West Chester State College in the fall to pursue a degree in teaching, but the college denied her admission on the basis of her illness, an acceptable policy in the 1950s.

An article by Steven M. Spencer in the March 1953 edition of the *Saturday Evening Post* entitled “No Wonder Epileptics Are Bitter” stated that “it was easier to find a job for an ex-convict than for an epileptic.” Despite the grim prospects, Betty continued to fight her disease and the side-effects of the medications. She was determined to overcome the stigma and beat the disease.

Betty graduated from high school near the top of her class, yet she was depressed and lonely. Betty changed from a bright, athletic, and outgoing young woman to a listless, moody, and terrified creature. Her friends had moved on with their lives and her mother did not want to understand the changes in her daughter. Mother and daughter often fought. Kathryn’s shame and anger obliterated sympathy and care at a time when Betty needed them most. Unable to fix or ignore the damage, Kathryn pulled away and disowned her oldest daughter.

Betty spent more and more time at the home of her friend Pam. When Pam got married and moved away, Betty went to live with Pam’s family for a year. Away from the rejection of her mother, Betty took control of her life, weaning herself from the medications which altered her personality and behavior. Betty chose between feeling “normal” for the ever-looming risk of seizure. She developed coping strategies. By recognizing the signs of an imminent attack, Betty was able to understand that most of her seizures occurred at night or as a reaction to certain stimuli.

Called an aura, the term was coined by the second-century Greek physician Galen. For epileptics, an aura does not mean a halo of light around

people or objects. According to Epilepsy.com, “auras vary significantly between different people.” They range from a sense of déjà vu to depression or irritability. An article entitled “Epileptic Consciousness: Concept and Meaning of Aura” published in *Epilepsy & Behavior* 8, concludes: “We are now tempted to define aura as a sudden experience of strangeness overcoming consciousness that indicates the beginning of a partial seizure.”

Betty learned to recognize her aura, a sensation she could not describe, but felt intensely. She learned to avoid flashing lights, ceiling fans, extremely stressful situations, and the thing that terrified her most, snakes. She chose to take control of her life by choosing her environment carefully.

Her next step was to enroll in nursing school; her desire to learn and be productive never waned. Nursing was one of the few acceptable vocations available and Betty was determined to remain self-sufficient. The hurt of abandonment never subsided, but with her illness under control, Betty returned to her family. She cautiously rebuilt the relationship with her mother and hoped for a future.

In 1956 Betty received her Associates Degree in Nursing from the Saint Josephs School of Nursing in Philadelphia. As a Registered Nurse, Betty began working at Chestnut Hill Hospital, the same hospital where she had begun her fight with epilepsy. The drive and discipline that pushed her through the worst of her illness helped Betty succeed in her career, moving through departments from

staff nurse in the Medical/surgical department to the Pediatric nursery to head nurse of the Intensive Care Unit/Medical Surgical department.

As she moved up the nursing ranks, Betty's personal life settled down. Charles "Skip" Hazell had always been Betty's fondest admirer. They had grown up together, meeting in the second grade and remaining close friends through the years. "Skip always loved Betty, he was always in the background, waiting for her," Pam recalled. Skip had enlisted into the United States Air Force, but a family emergency called him home, ending his dream of becoming a pilot. They resumed their friendship as he took over his father's luncheonette business. Betty was still harboring the heartbreak of her first love, Tony, but Skip was solid and kind. His adoration won her over. They married on May 24, 1957.

The next step was a family, but Betty was committed to her career. Her fear of being dependent, of losing control inhibited her becoming a housewife. The damage caused by her illness lingered. Betty needed to prove she was better than her peers. Although she was an excellent cook, could bake delectable desserts, and sew her own clothing, her fear of losing her ability to work, her terror of being sedentary, kept her working.

When their first daughter, Anne, was born in October of 1959, Betty was faced with another challenge. During the birth, Anne aspirated some amniotic fluid. The liquid caused an infection in the infantile lungs. Anne required blood transfusions. The threat of losing her baby overwhelmed Betty. The specter of her touch-deprived childhood and the emotional self-preservation she had mastered

with epilepsy took over. Like her own mother, Betty could not bear the thought of a damaged child. She refused to hold the infant or bond with her until assured of Anne's survival. Skip and Betty brought Anne home, but Betty was never comfortable with traditional motherhood. The small family moved to a house closer to the Hazell family business, the house where Skip spent his childhood. Betty returned to nursing, resuming her position in the ICU part-time.

In the early 1960s, the Intensive Care Unit of Chestnut Hill Hospital was crowded, but well staffed. An article by Julie Fairman titled "Economically Practical and Critically Necessary? The Development of Intensive Care at Chestnut Hill Hospital," tells how the unit "had become a 'runaway' idea: it had taken on a meaning and purpose not originally anticipated, and created new sets of problems." Reflecting the nursing shortages common in 1950s hospitals, unskilled aides were trained on the job and skilled nurses were pulled from other departments to fill shortages. As Fairman wrote, "In turn, intensive care nurses spent a great deal of time supervising less-skilled, temporary workers". This is the environment in which Betty worked. As the supervisor of the growing unit, Betty taught inexperienced nurses and matched skilled nurses with those less able. The pressure was immense, but Betty found she enjoyed the challenge.

As the head nurse, Betty also was able to observe and participate in the development of the unit. The hospital developed and implemented intensive care earlier than their competitors, including many Philadelphia hospitals associated with elite medical schools.

Her career was on track and Anne was growing. Skip and Betty considered having another child. For years, no pregnancy followed. The main cause of the couple's infertility was the medication Skip took for hypertension or high blood-pressure. The medicine reduced Skip's sperm count making a natural pregnancy nearly impossible. Betty chose to undergo artificial insemination, the only available option in the 1960s. The process was humiliating, uncomfortable, and resurrected memories of her epilepsy treatments. She was required to lie on a metal table with her feet strapped into gynecology stirrups, and be examined and prodded by a team of male doctors. Skip and Betty also considered adoption. They were preparing to adopt an infant boy, when, in early 1968, at the age of thirty-six, Betty finally conceived. Their second daughter, Nancie, was born nearly nine years after her older sister.

The new baby caused a major upheaval to the family. Betty went back to work a year after the birth, taking the stressful night shift at the hospital. "She would sleep during the day a bit and then for a couple of hours before work," Anne remembered. "Though one day, I got dropped off from school and the door was locked. I kept knocking to wake Mom up or have [Nancie] let me in, but [she] was too young. My friend's mother was watching and I thought she must be wondering what kind of mother I had." Anne knew her mother was unlike those of her friends. Anne would joke, "My father is my mother and my mother is my father." The girls would check in and stay around the luncheonette after school, while Betty worked. The night schedule was too much for Skip and ten-year-old

Anne. The baby kept them awake at night, Skip went to work exhausted and Anne arrived at school sleep-deprived. Betty changed her schedule to days, the baby spent the time either at day-care or at Skip's store.

When Betty moved on with her career, both of her children were in school. She took a position at the Medical College of Pennsylvania (MCP) as an Administrative Supervisor. Her experience in Chestnut Hill Hospital's developing ICU prepared her to instruct critical care nurses. At the same time, Betty returned to school. In 1976, Betty received her Bachelors of Science in Nursing from Gwynedd Mercy College, a suburban Catholic college.

Long hours working, attending classes, and studying left Betty little time with her children. Like Kathryn, Betty expected scholastic excellence, but unlike her own housewife mother, Betty was not home enough to monitor her daughters. Skip was the caretaker who tried to encourage the girls to finish their homework. Betty was the disciplinarian. "Wait until your mother gets home," was heard whenever the girls broke the rules or produced a bad report card.

Betty had a temper and a cruel streak. Anne was diagnosed with a conceptual difficulty in math. One day while grocery shopping with Anne in tow, Betty was drawn into a conversation with a woman waiting in line. When the subject of children was broached, Betty offered an unwarranted explanation of her child's fault. "We didn't expect much from our Annie," Betty replied, "we thought she was retarded." Although Betty seemed to mean that Anne's difficult birth could have impacted her brain development, Betty's words stayed with

Anne. Verbal lashings were a defense mechanism against Betty's own insecurities that wounded her daughter.

Although her position at MCP was challenging, clashes with co-workers and executives muted the enjoyment she gleaned from the work; she did not feel she fit in. After securing a position at another area hospital, Montgomery Hospital, as their Director of Education and Development, she dished out her displeasure. On one of her last days at MCP, Betty baked a cake for her "favorite" executive. Betty was an accomplished baker, so she whipped up a special chocolate layer cake. Instead of flavoring the batter with pure cocoa, Betty added a hefty dose of chocolate-flavored Ex-Lax. The cake was perfect and the victim commented on how delicious it tasted. When Betty, years later, repeated the story to friends and family, tears ran down her cheeks as she reconstructed the memory of the executive's comment. "He let me know the next day," Betty laughed, "he said, 'Gee, Betty, that cake was absolutely delicious, but I'm really sorry I couldn't finish it. I like it, but it sure didn't agree with me.'" The mischievous streak rarely emerged in Betty's personality, but she had retained some of her humor and spunk.

A year after completing her BSN degree, Betty decided to take her education further. Her disappointment in not fulfilling her dream of teaching had evolved into an interest in nursing education. She was accepted into New York University's graduate program. The school was in New York City, however, two hours from her home in Philadelphia. Skip's business was thriving, but did not

provide enough income to support the family. Betty worked long shifts to enable her to attend classes twice a week. On school mornings, Betty woke before dawn. Skip drove her to the nearest train station before heading to the store. Later that night, he and the girls would meet her at the train. It was a grueling schedule. In 1980, the hard work and family sacrifice paid off. Betty was awarded a Masters of Arts in Nursing. Reflecting her struggle, her thesis was entitled, “Epilepsy, an Evolutionary Emergent.”

Epilepsy was never far from Betty’s thoughts. She never let her guard down or her control lapse. Once, at the wedding of one of her daughter Anne’s close friends, Betty allowed her control to slip. She drank two glasses of wine. Unaccustomed to any amount of alcohol, the sudden tipsiness triggered a seizure. While having fun, Betty ignored the signs of the impending attack. She fainted. Although, it seemed a small event, it was the first seizure Betty had suffered publicly in decades. Afterwards, Betty rarely drank anything alcoholic; she would take small sips of wine when her stomach was upset, but nothing more. Betty controlled her epilepsy so successfully that Nancie only saw her mother faint once in the midst of an argument and Anne remembered one close call while shopping at a local mall, referred to as the “snake incident.”

Betty’s fear of snakes was extreme. In high school, when her seizures began, a rumor circulated that they were triggered because her younger sister snuck a snake into Betty’s bed. She couldn’t look at them even when they were on television; if there was the slightest glimpse of one, the channel would have to be

changed or Betty would rush from the room. On the day of the “snake incident,” Betty, Anne, and Nancie were together, a rare occurrence after Anne’s departure for college. The Hazell women went to a mall to do some shopping. Nancie slipped into the pet store to buy food for her rabbit while the others waited on a nearby bench. The pet store manager happened to be strolling around the shop with a large boa wrapped around his neck. When he approached the front of the store, Betty glimpsed the snake, exclaimed, “Oh, no,” and jumped up to move away. The manager followed her. The man seemed to enjoy Betty’s fright. Anne stepped in front of him, blocking his path and angrily explaining her mother’s condition. The manager shrugged and returned to the store without apology. Betty had escaped to another bench, shaded by a tree and was taking measured, deliberate breaths while holding her head between her knees. She stayed there for nearly five minutes. Betty inhaled deeply and declared herself fit to resume shopping. The close call was not enough to deter Betty from her planned activities.

Professionally, the Master’s Degree did not satisfy Betty’s ambition. She still harbored the hurt and rejection of her illness. She felt she had more to prove. Although she had advanced through positions as the Assistant Director of Nursing at both Temple University Hospital and Thomas Jefferson University Hospital, she wanted to do more. Betty dreamed of being a millionaire. Money became a motivation. Power and money became Betty’s measure of success; they became the means to force the respect of others. Education only fueled her determination

to take on larger challenges, to prove to herself and those who had shunned her that she could accomplish more than they imagined.

Betty took a job in Williamsport, Pennsylvania, three hours and twenty minutes from home. During the week, Betty lived alone in a rented apartment. Every weekend she would return to Erdenheim and her family. Although the Williamsport Hospital was smaller than the Philadelphia hospitals, she was now a Director of Nursing, which allowed her to implement her ideas about patient care and better nursing. It offered more power and better pay.

Betty reveled in her independence. But her strong, uncompromising vision for the hospital was not embraced by her fellow executives. She felt nursing staff were frequently overlooked by hospital administration. According to Betty, doctors were given too much power in hospital protocol. She did not deny their education and skill; rather, she saw nursing staff as an essential part of the patient care team, not simply unskilled assistants. Betty was persistent and outspoken when advocating for her fellow nurses; she knew how the hospital should be run and was willing to fight for her ideas. After two years, it was becoming obvious that it was time for her to move on. She had done all she could to improve the nursing practices of the hospital.

When offered a position as a Vice President of Nursing by St. Mary's Hospital in Langhorne, Pennsylvania, Betty decided to move back to Erdenheim. Her belongings were packed up and taken by Skip, but Betty spent one final night alone in the apartment she loved. As she slept, an intruder broke in through a

window. He held a knife to her throat. She couldn't see his face. It was dark and she was alone. After the attack, Betty rushed to the hospital, was examined and reported the crime to the police. Skip rushed back to Williamsport and brought Betty home. She was shaken, but refused to speak much about the incident. It was tucked away into her memory, buried with traumatic memories of her disease. Her rapist was never caught.

Betty was not happy at St. Mary's. True to form, Betty moved on to her next opportunities. After a brief stint with a home health care company that allowed Betty to travel around the country, she was recruited as the Vice President of Patient Care Services for Palisades General Hospital in northern New Jersey. The job required Betty to commute again. She also rented a small apartment, but this time she was more cautious. She installed dead bolts on the doors and braced the windows.

In 1986, Betty's eighteen-year old daughter, Nancie, discovered she was pregnant. Betty was livid. She had just bought a new Ford Bronco and was planning to buy a horse trailer for Nancie's horse. Betty enjoyed the prestige of Nancie's equestrian pursuits and gave Betty an excuse to buy a large, intimidating vehicle. Teenage parenthood was not part of Betty's plan for her daughter's future. Angry, but determined to make the best of the situation, Betty's first trip with her new Bronco was to bring Nancie home from college. Skip came along to drive his powder blue VW Bug back to Philadelphia. He had lent the car to Nancie so she would not be stranded at school.

On the return trip Betty and Nancie were in the Ford, Skip and Anne pattered behind in the Bug. Betty loved to drive fast. She was reveling in the power of the Bronco's V-8 engine, but Skip's car could not keep up. Betty was annoyed that she needed to pull over every so often to wait for him. The vehicles approached a seven-mile steep decline. Betty let the Bronco go. Nancie watched the scenery flash by faster and faster. The blue Beetle faded from sight. She became alarmed. "Mom, how fast are you going?"

Betty looked at the dashboard and answered calmly, "I'm only going 35. Why?"

"You can't be."

"Look right here." Betty pointed to the gauge in the center of the console.

"Those are the r.p.m.s. The speedometer is on the left. You're going almost 100mph! "

Betty rolled her eyes and tapped the brakes, gradually slowing to eighty miles per hour, but she never admitted she was wrong. At the end of the hill, mother and daughter pulled into the parking lot of a restaurant where the family had agreed to stop. The pair waited for the Beetle to arrive. When it sputtered into the lot, Skip's face was red with fury. Anne's teeth chattered from the lack of heat in the car and speedy descent. Betty stared right back, smiled, and shrugged.

She was now in her fifties, but Betty refused to slow down. Skip, however, was beginning a battle to survive. A physical revealed abnormal polyps in his colon. At first, his daughters were unconcerned. Anne, who accompanied her

father to the hospital to have the polyps removed, repeated the assurances her mother had voiced. “Ok. They take them out and he’ll be fine.” But the polyps were cancerous and Skip was scheduled for radiation treatment. The radiation drained Skip, but he continued to run his store, waking at five-thirty each morning and working until five in the afternoon.

The radiation was only marginally successful. Skip’s cancer was still spreading. A course of chemotherapy was effective against the cancer, but fatigue and illness interfered with his ability to work. He could not keep the store, his vocation, running properly. Betty needed to make a choice between her job and her sick husband. While she was trying to support her husband long distance, leaning on her oldest daughter to help care for him, Betty was offered a high-level administrative position at a hospital in Texas. Together, they made a decision. Skip left his store, sold the business, and moved with his wife to McAllen, Texas. They packed up their furniture into a U-haul and drove together from Erdenheim, Pennsylvania, to their new home in Mission, Texas.

The long drive across the country was memorable. The couple enjoyed the long hours on the road and the chance to see the country. It was the closest thing to a vacation the couple had taken since the birth of their children. The luncheonette had always tied Skip down and Betty’s work had consumed her life. As they passed into Texas, Betty began to imagine a different path. For the first time, she could envision retirement. Her new-formed dream was to buy an RV and take Skip on long drives around the country.

Once in Texas, Skip's cancer returned and he began a second course of chemotherapy at the hospital where Betty was the Chief Nursing Officer, one of the top three positions. She traded in her white Ford Probe for a large conversion van, a first step toward her vision of travelling with Skip. Even with such a cumbersome vehicle, Betty continued to drive as if she was drag-racing and the flat, straight highways of Southern Texas were an ideal track. On one occasion, Betty was pulled over by a Texas State Trooper. When the officer approached the van he informed her that he had clocked her cruising along at seventy-two miles per hour. Betty laughed and cheekily suggested that he get his radar gun recalibrated. "I was going a lot faster than that," she replied. To retain her license, Betty was required to attend safe-driving classes.

Despite the shadow of illness, both Betty and Skip loved their new A-frame house and the hot southern Texas weather. Skip volunteered at the hospital when he felt well. At home, while Betty was at work, he mowed the lawn and cared for their three dogs. His cancer was spreading. A colostomy was performed. With the removal of such a large section of colon an incision was made in Skip's abdomen wall and his body's solid waste was collected in a bag. Occasionally, the bag would leak or overflow, causing embarrassing odor or stains. It was a humiliating device, but Skip accepted his new situation with his characteristic equanimity. He continued with his chemotherapy to combat new tumors discovered in his lungs and his brain. His oncologist gave Skip six months to a year left to live.

Regardless of her husband's prognosis, Betty continued to work. She had beaten her own illness and expected no less from him. In a strange way, she thought if she acted as if nothing was wrong, if she continued to encourage Skip to enjoy his life and push him to fight the disease, he would survive. And he did.

For three years, they continued a routine. Skip would putter around the house until Betty came home from the hospital; they went to dinner or visited new friends. For vacations, rather than take long road trips in the van, they returned to Pennsylvania to visit their children and grandchildren. Betty seemed oblivious to Skip's deterioration. Their children were shocked by the changes in their father, noting his wasting thinness, his unhealthy pallor, and weakness. Betty assured them he was doing well. Regardless of his poor prognosis and appearance, Skip passed the year survival mark by two years, but the cancer was still spreading.

In August of 1993, Skip's deterioration was undeniable even to Betty. Weakness limited his movements to the first floor of the house; a walker helped him move between rooms. His world collapsed to mainly the kitchen and the adjoining living room. A milkshake and peanut-butter crackers fed him through the day, but he wasn't hungry. Within days his body had weakened enough that Betty contacted the local Hospice and ordered a hospital bed, which was set up in the center of the living room to allow Skip to watch television. In mid-August, Anne and Nancie flew in to reconnect during his final days. At first, Betty was angry with her daughters. "He's okay. It's not time yet," she told them, but Anne

had heard the change in her father's voice, notified Nancie and insisted they fly to Texas.

Skip lapsed in and out of consciousness and near the end of the week, began the harsh breathing called Cheyne-Stokes, which signaled impending death. One evening, everyone was gathered in the living room around the bulky hospital bed. Anne and Betty sat on the couch, while Nancie sat in a blue recliner. They tried to watch a movie, but the loud breaths interfered with their concentration. Betty remarked, "Well, this is like old times. Isn't it? It's just like when your Dad used to fall asleep in front of the television." They laughed painfully. Humor was Betty's way to fend off the strong emotions that were one of her seizure triggers. But Skip again defied the odds, lingering in his coma well beyond the forty-eight hour window predicted by the hospice physician.

A few days later, while her daughters were out filling the water jugs for the cooler, Betty sat by Skip's bed, holding his hand. "It's okay, Skip," she said. "I'll be alright." As if waiting for her permission, he took a few final breaths and died.

Skip's loss changed Betty. Despite the opportunity and pressure to retire, Betty continued to work. Widowhood freed her to acknowledge her career as something she enjoyed, rather than a badge of honor, or a way to prove she had conquered her ever-present disease. By recognizing her triggers, Betty had avoided public spells for the past decades. The few seizures she suffered occurred

in the middle of the night; the only evidence was wet bed sheets. It was humiliating, but secret.

Betty learned to run the lawn tractor, woke earlier each morning to care for the dogs, and even learned how to deal with an occasional snake. Determined to maintain a life she loved, in a house she cherished, Betty persisted. At work, tensions between the hospital administration and the board of directors were building. Her forceful personality and strong views on hospital management, however, did not win her many friends on the board of the directors. Her drive and willingness to work long hours overtime incurred the resentment of those who thought the status quo was acceptable. She made them look bad.

Another problem was escalating. Betty's home was located in a rural community close to the Mexican border. While violent crime was rare, thefts and vandalism were rampant. Betty was forced to have gates and bars installed around every window and door of her house as well as an electric gate at the bottom of the driveway, but she was still robbed a number of times, losing a water heater and air conditioning unit in separate thefts. She had hidden most of her valuables, but in one break-in most of her jewelry disappeared.

The hospital began a search to replace Betty and they encouraged her to retire by offering her a generous severance. They wanted her out. She no longer felt safe at home and her daughters were pressuring her to move somewhere more populated and less vulnerable. It was a logical choice for Betty to retire, but it was the last option she was willing to consider. Instead, at the age of sixty-two she

looked for a new challenge and found it in the small community of Safford, Arizona. A moving van carted furniture and Betty's large wardrobe from the home she loved to a rental in Safford. Betty drove her conversion van the long distance with only her three dogs and cat for company.

She settled into a rented three-bedroom house situated in a quiet development at the end of a cul-de-sac. The dogs had the run of a small fenced yard. While Betty was at work, the dogs were left outside. Betty bought each dog a large house, and she made an arrangement with the boy next door to make sure they had plenty of water.

When Betty arrived, Mount Graham Hospital was a small community hospital, in the process of expanding into a regional medical center. One of the first improvements was a much-needed update to their imaging capabilities. The 1990s saw an explosion of imaging technology with improvements in Computed Tomography (CT) scanners and Magnetic Resonance Imaging (MRI). These two tools allowed physicians to image the body with precision and digital clarity. To accommodate these bulky and expensive machines, the hospital constructed a new building to house a nuclear medicine department. As the facility neared completion, an MRI machine was ordered. Months passed and the equipment did not arrive. The administration tried to address the problem with letters and phone calls to all of the parties involved. As frustration grew, Betty decided to confront the problem in her own manner. The MRI machine was manufactured by General Electric. With persistence, Betty called GE offices in both medical divisions and

administrative offices. Her campaign did not end until she had contacted the highest levels of the company. When the problem remained unsolved, Betty took the matter farther. Her relentless efforts paid off. After a phone conversation with Jack Welch, the Chief Executive Officer of General Electric, the ordered MRI arrived in Safford, Arizona. Betty's persistence paid off. The new MRI was accompanied by a Dual-Head nuclear medical camera, which had been sent to compensate for the misunderstanding and delay.

The Southwestern weather appealed to Betty as much as her career challenges; a fiery attitude did little to warm her tiny frame. To Betty, eighty degrees was barely warm enough, ninety and above was perfect. Once her work schedule became routine, Betty decided to add to her pet family. She bought a Vietnamese Pot-Bellied Pig and she named it Bacon. "Well, after all," she explained, "I had a dog named Piglet so I couldn't call the pig that. I like [Bacon] and he doesn't mind. If people are offended, I tell them his name is Bacón." Bacon was given a tarp-covered area in the back yard. Betty loved her pig, but unfortunately he developed a recurring health issue. His rectum prolapsed, a condition where the inner structure of the intestine is pushed outside the body. The first time, the veterinarian was able to manipulate the tissue back into place. When it happened a second time, Bacon's rectum was surgically repaired, but when it recurred a third time, the veterinarian advised against further surgeries. Betty was forced into a difficult decision. After a year and a half together, Betty

had Bacon euthanized. She bought a small ceramic pot-bellied pig in remembrance.

During her tenure at Mount Graham, Betty made a lasting friendship with Sally Schlautmann. “I met Bettyann in April 1995 when I interviewed for a position as secretary at Mt. Graham Community Hospital,” Sally recalled. “We spent many hours together at work, at meetings and social events in the community of Safford.” Sally described Betty as a demanding boss. “She did have a bit of a temper and would get riled up when employees failed to fulfill the duties their positions required. She didn’t mind stepping on toes if it meant getting the job done.” But Betty only expected from others what she demanded from herself. Although working twelve or more hours a day, according to Sally, Betty “was sensitive to the feelings of her employees and often spent her holidays at the hospital with those scheduled to work. She always made sure they were remembered with special meals and celebrations for each holiday.”

Betty made a new life for herself in Safford, but her family was over two thousand miles away. Although she visited them as frequently as possible, she was once again torn between work and family. Anne had married and remained in the Philadelphia area with her husband and two children. Nancie was living in Vermont with her son. Nancie’s move to New England reignited Betty’s desire to own a farm. In 1995, Betty purchased “Winterwind Farm,” a five-acre property in Chester, Vermont, complete with an eight-stall barn, a riding ring, paddocks and a small pasture. It was her idea to retire to the farm when she was tired of working,

and her daughters thought the purchase would hasten Betty's withdrawal from the career world. They were wrong. Instead, the farm provided another excuse to keep working. "I have to work to keep this enterprise going," she would tell her daughters.

In August of 1997, Betty's daughters and grandchildren flew to Arizona to celebrate her sixty-fifth birthday. Betty wanted them to take advantage of their long trip by showing them around Arizona. The group spent hours in the van driving from Safford to Phoenix and Tucson, visiting places like Boot Hill, Tombstone, and the Sonora Desert Museum. At the end of the week, Anne and Betty, with Anne's children in tow, were exploring Phoenix. They stopped at an RV store. After touring many motor homes, Betty impulsively bought herself a thirty-four-foot birthday present.

To justify her large purchase, Betty moved from her rented house and had her Bounder motor home delivered to an upscale trailer park in Safford. Her largest dog, Buddy, was given to the neighbor who had always cared for the pets when Betty was away. It was a difficult decision, but he was simply too big to live in the cramped space. With her small black and white Shih-Tzu mix dog, Piglet, and her orange tabby cat, Tigger, Betty put her extra clothes and possessions in storage and moved into her RV.

At the hospital, Betty applied her research and knowledge by recruiting specialty physicians for the growing internal medicine, surgery, orthopedic, and medical oncology and radiology departments. She remained active in the design

and operation of the expansion project. According to the Eastern Arizona Courier on September 5, 2007, Betty “was instrumental in the expansion and renovation project that resulted in the hospital’s becoming a regional hospital.”

Unfortunately, Betty’s personality and strong opinions were, once again, not appreciated by those in charge. In 2001, while performing the duties of the absent Chief Executive Officer, the hospital board began to seek a replacement for Betty. Although generally respected, Betty was not the type of CEO the hospital desired; many of the established administrators resented being pushed around by a tiny, brash female. One of the hospital’s health educators, Kristi Claridge Fertig, described the divide between the nursing staff and the hospital administration. Kristi was hired by Betty and “spent the next few years under her guidance and direction.” Kristi “learned so much from [Betty] and really enjoyed her honesty and straight forwardness. In this small town, that’s a nice change from the good ol’ boy system.” Betty refused to act like a “good ol boy” and made the executives look bad. Members of the hospital administration had cited Betty’s age as a reason for her dismissal. Essentially, board members had hoped to convince Betty to accept a retirement package. After all, she was nearly seventy years old, but Betty was not easily bullied and she “expressed in no uncertain terms exactly what she thought of their decision.” Members of the security staff accompanied Betty to the door.

Her reaction to her ignominious termination was to file a discrimination complaint. The lawyer she hired, Lawrence Fleischman, was a respected former

judge who specialized in alternative dispute resolution. The oldest practicing lawyer in the county, he negotiated a settlement out of court. The Eastern Arizona Courier interviewed Betty and published an article on August 8, 2001, four days before Betty's seventieth birthday. In the article, Betty stated that she felt betrayed by those she trusted. She also said: "If I could leave a legacy it would be that we address issues of concern and we resolve them fairly." Those public words conflicted with a piece of advice Betty bestowed upon Kristi Claridge Fertig, words Kristi "always thought were funny coming from my boss- 'it's better to ask for forgiveness than for permission.'"

Betty was seventy-years old and unemployed. She had a farm in Vermont, where her youngest daughter lived until Betty would decide to retire, but slowing down was not Betty's desire. Instead, she used her experience as a marketing tool and accepted a position at St. Vincent's Hospital in Leadville, Colorado. Dave, Betty's son-in-law, and his son Joshua, flew to Arizona and drove the Bouncer back to Pennsylvania. Betty's Jalapeno-green Ford Ranger, affectionately called Pepé, was also dragged east.

Once again, Betty loaded Piglet and Tigger into her new, unnamed red Ford Ranger XLT 4x4 and drove to Leadville, a former mining town, and the highest incorporated city in North America. Although Leadville boasted 310 days of sunshine, Betty was forced to adjust to colder temperatures and thinner air found at 10,430 feet. Her new home was part of a rural development called

Beaver Lakes, A front deck overlooked the dry lakebeds and a spectacular view of Mount Elbert and Mount Massive, the two highest peaks in Colorado,.

Her new job was Director of Nursing/Chief Operating Officer and with her usual energy, Betty integrated herself into the hospital staff and the community. In her spare time, she taught Anatomy and Physiology at Colorado Mountain College's Timberline Campus, but the rural setting and slower pace of Leadville sparked a change in Betty. On the warmer weekends she enjoyed taking Piglet for long walks along the dirt roads of the Beaver Lakes community; on cold days, Betty took up her knitting needles and began sweaters, scarves, and hats. The nearest larger town was an hour away, forcing her to consolidate trips for groceries and household essentials. Betty was learning to relax.

When her daughters and grandchildren came to visit for Betty's seventieth birthday, Betty drove to Denver to meet them at the airport. The family rented a second car, since Betty's small truck had only space for four people. Anne, her daughter, Sammi, and Nancie drove the rental, while Anne's son, Josh, and Nancie's son, Alex, rode with their grandmother. Anne and Nancie had steeled themselves for a tense time as Betty frequently applied her administrative ideals and forceful personality to family visits. In short, Betty was controlling, becoming irritable when her plans or ideas were questioned, and it was difficult to predict when she would snap. Her daughters placed bets on how many hours it would take for the kids to annoy their grandmother. On the return drive to the airport, Betty stopped at a pull-off to allow the boys to switch seats. A hitchhiker

approached her vehicle. Anne, Nancie, and Sammi watched in horror as Josh and Alex squeezed into the back seat and the hitcher was invited to sit in the front. Before, the daughters could react, Betty's truck returned to the highway. Anxious and helpless, they followed the pickup to the next town, where it pulled over, the stranger got out and Josh returned to the front seat. At their final destination, Alex told his mother about the incident. "She said to the man, 'You wouldn't kill a little old lady and her grandchildren, would you?' He said 'no.' So she told us to get in the back and gave him a ride. It was funny."

In Leadville, Betty befriended Jim O'Neal, a native to Leadville, who was once the town's mayor. It was the first time since Skip's death that Betty spent time in the company of a man. The pair went to community functions together and Betty was a frequent guest for dinner at Jim's son's house. Betty enjoyed his companionship; however, Jim was in his eighties and depended on a walker and scooter for mobility. One of Betty's prime complaints was maneuvering Jim and his scooter in and out of her truck. Betty would grumble, "I'm not a very big person and that scooter weighs nearly as much as I do." Jim's age and infirmities reminded Betty that she, too, was aging.

For three years, Betty lived and worked in Leadville, but the pull to return East was constant. In early 2003, Nancie was diagnosed with Malignant Invasive Nodular Melanoma. Surgery successfully removed the cancer, but Nancie was encouraged to undergo a year of Interferon therapy. Betty took a leave from the hospital and flew home for three weeks to be with her daughter. Nancie's illness

forced Betty to evaluate her options. Although she was now seventy-three, Betty felt she had more to offer and began to search for a job closer to her daughters. Despite her age, she was invited to several interviews and accepted a position at Greenfield Area Medical Center in Ohio. Betty and the pets took another lonely cross-country drive.

Betty was hired as interim director, but was asked to stay on as Director of Patient Care Services. After two years in Ohio, Betty realized two things. First, she wanted to move to Vermont or Pennsylvania, but hoped to keep working even part-time, and second, she was seventy-four years old.

On a Thanksgiving visit to her farm, Betty toured the small Grace Cottage Hospital in the tiny hamlet of Townsend. Although Grace Cottage was significantly smaller than any other hospital where Betty had worked, she sent them a resume. In January of 2007, Betty was offered a position. Shana Jones, the CEO of Grace Cottage was confident that Betty was the right woman to be the director of nursing. “She was quite a dynamo. She had every faculty to do what she needed to do.” Betty was finally moving to Vermont.

Betty moved into her sister’s apartment, half of a converted farmhouse. The three-bedroom second-floor domicile was crowded with the belongings of both women and Betty’s new dogs, Reilly and Pita. Betty was well-known for her extensive wardrobe; she hated wearing the same outfit twice. While sharing the apartment, Betty was forced to keep most of her clothes and other belongings in a rented storage unit. Each weekend, Betty, Snooker, and Nancie would swap out

clothes, replacing the worn outfits with new. When the downstairs tenants moved, the landlord removed a partition dividing the apartments and Betty moved downstairs. For the first time in fifty-seven years the sisters were living together.

One love they shared was tennis. Snooker played, Betty watched. Unable to compete because of her epilepsy, Betty retained her love of the game and her favorite player was Pete Sampras. Betty taped every match he played and kept a scrapbook of articles and interviews chronicling Sampras' career. Once, during a visit to Pennsylvania, a friend arranged box seat tickets to a match in Philadelphia. Betty went to the game, but turned away from the play, afraid to watch if he lost. After the match, the friend attempted to arrange for Betty to meet Sampras. They almost missed him, but as he was leaving the stadium, Betty was able to shake hands and get his autograph. The signed program went into the scrapbook and a photo of the event hung proudly on the wall of Betty's office.

Every year, Snooker was given tickets to the Pilot Penn Tennis Championships in New Haven, Connecticut. Betty left work early to attend an evening match. After parking her new Toyota Tundra—bought because she wanted a bigger, more powerful truck than her Ranger—she dashed inside to change. Snooker packed her own Ford Focus wagon for the trip. While inside, Betty left a quick message on Nancie's machine. "Hi. This is just your mother. Would you let the doggies out when you get home? We're going to be out late." Betty slid into the passenger seat and the pair set off to New Haven.

At 1:30AM, on their return from Hartford, Betty and her sister were killed by a twenty-one-year old drunk driver who had been travelling at over one hundred miles per hour.

First to the scene of the accident was a Connecticut State Trooper who had been positioned at a nearby construction zone. When the emergency crews arrived, Trooper Joyal watched the teams of medical technicians attending the victims. Betty was lying on the hot pavement a few yards from the crushed car. She had only a small laceration on the side of her head.

Officer Joyal later reported to the family, "I saw them load her into the ambulance and was sad to hear she had passed. I really thought she would make it. She looked like a fighter."

MELISSA

A lone voice rang out in the sun-bright room. “Busted flat in Baton Rouge, waiting for a train, and I’s feeling nearly as faded as my jeans.”

Drawn by song, visitors entered the white Victorian house, moved into the dim kitchen, through the purple-walled dining room, and came to the cream-colored sitting room. Gauzy curtains softened the afternoon daylight, comfortable furniture rested against the walls. An adjustable bed dominated the center of the room.

The smell of burning sage, cedar, and cigarettes buzzed in the nose. Fresh flowers offered a weak undertone. The song had started softly; a slight humming at first, the tune built, until it bloomed and filled the room.

“Freedom’s just another word for nothing left to lose.” Melissa Patterson reclined on a mattress and belted out lyrics made famous by Janis Joplin. Family and friends gathered around the pillow-topped stage, fans for a unique performance.

Like Joplin’s bluesy tone, Melissa’s voice was edged with nicotine and opiates. Bloating by the residual effects of a course of high dose steroids, Melissa looked the part of a burned-out rock star. Her dish-water blonde hair was cropped short in a simple, unflattering cut for easy care. She could no longer raise her

arms high enough to brush the once luxurious, bright gold length. The limp strands fluttered with the rhythm of the song.

Imprisoned by a body that no longer listened to her will, Melissa was sentenced to life in her full-size adjustable bed, lying in the center of the room she had painstakingly decorated months before. Her sanctuary was a cage.

Melissa paused for a breath and demanded, “C’mon, people. You know how to sing it.” But her audience stayed mute. She launched back into the tune. “And feeling good was good enough for me,” her weak body shook with joy as she abandoned herself to the song. She had nothing left to lose.

The tune rose and fell, loud then soft. At last, the volume dropped, fading out like a recording. Melissa’s voice evaporated. High doses of morphine and methadone blunted concentration; her nerves soaked in a pain-killing opiate bath. She closed her eyes, overtaken by sleep that was unconsciousness, not repose. Yet, for that moment, on a small cul-de-sac in Springfield, Vermont, in her crowded first-floor bedroom suite, Melissa was free.

Melissa Patterson was twenty-five years old when the pain in her neck became unbearable. She had fallen from a horse eighteen months before, an accident that whipped her head backwards. The fall was not spectacular. Melissa was a competent rider, a former guide for touristy trail-rides at her father-in-law’s farm. She was adept at instructing guests, entertaining them, and controlling her own mount simultaneously. On the day of her fall, she was alone, “legging up”—

exercising the horse—to prepare for the summer tourist season. The horse spooked and bucked. Melissa landed sharply on her rear and fell back. Her head, protected by a riding helmet, hammered the road. Her pride hurt as much as her neck.

She was born in Sacramento, California on June 20, 1971, to Michael and Linda Patterson. Blonde, blue-eyed, a slender five-foot-six, with freckles sprinkled across her small nose, Melissa resembled a Barbie doll, but that benign exterior masked a fierce spirit.

“Melissa and I grew up together,” Linda said of her daughter. “She taught me a lot. She was stubborn. I remember, she couldn’t have been more than two. She’d made a mess in her room. I was more anal then.” Linda laughed, though her subsequent homes remained clean and ordered. “I told her to pick up her toys. She just stood there and said, ‘no.’ I repeated, ‘pick them up.’ Again, ‘no.’ Three or four times I asked. ‘No, no, no, no.’ I was getting more and more angry. I spanked her. Still, she refused. She made me so mad it scared me. I knew that no matter what I did, she was not going to pick up those toys. She would have taken it to the ‘nth degree. Mike came in and calmed me down, told me to let it go. I learned then that I couldn’t deal with her that way. You couldn’t take her head on. She would defy you.”

Linda separated from Mike, went to work for the State of California, and met Steve Hernon. When the divorce was finalized, Steve and Linda married and moved across the country. They bought a natural foods store in Andover,

Massachusetts. Melissa lived full-time with her mother and step-father, flying back to California to visit Mike during the summer months. Linda and Steve enrolled Melissa in the Lexington Waldorf School, which offered an education balanced between art and academics. Waldorf education enhanced the values Melissa learned at home; creativity and self-reliance were encouraged.

In 1992, Melissa moved to Vermont with her boyfriend, John Ells. His family owned a rustic cabin with no electricity or plumbing. Melissa was the kind of girl who could live in a cabin with no heat or running water, fix her own car, last through the day on an apple and water, and still outwork most men. But when she ended her relationship with John, she was homeless. Melissa did not worry; she stayed with friends and sometimes slept in her car. She began dating her boss's son, Paul "Chip" Kendall and soon moved in with him. Months later, when she discovered she was pregnant, she organized her own "shotgun" wedding. Melissa created the vision and the plan; Steve and Linda did the legwork and paid the bills. Friends and family strongly advised her to rethink marriage to Chip. They argued that he was comfortably rooted in tradition and routine, characteristics which clashed with Melissa's capriciousness. Opinions did not matter. Strong-willed and fearless, Melissa always did things her own way.

For months following the fall, Melissa stopped riding and avoided activities that strained her sore neck. It was a challenge for an active twenty-five year old. She loved to move furniture and decorate her home. She typically worked two jobs and balanced a hectic schedule with the pressures of parenting

her toddler son, Christopher. Chip was busy helping with his father's riding stable and running his own maple syrup business, Kedron Sugar Makers. Melissa stayed inside and designed labels for the fancy glass syrup bottles. She took orders and sent them out, spending hours on the phone and in front of a computer screen during the precious months of summer. Melissa tried to wait out the pain.

Regardless of her efforts to allow her neck to heal, the discomfort remained.

Melissa considered a trip to a "normal" doctor only as a last resort. Her mother and step-father, as owners of a natural foods store, believed in homeopathy and natural treatments. Arnica and Echinacea were used before Ibuprofen or Pseudoephedrine. Melissa was raised to consider less invasive, alternative medicinal options before consulting "Western" doctors. For the neck pain she went to a chiropractor.

Randy Schaetzke, chiropractor and naturopath, listened to Melissa's symptoms and did a brief examination, before telling her he "would not touch her without x-rays." Reluctantly, she went to a small regional hospital where two films were taken. Doctors found an abnormality on the radiographs, an odd curve to Melissa's trachea. Dr. Schaetzke thought the bulge on the image was caused by inflammation. His best guess was that Melissa was chronically reinjuring the area. He gave her a cervical collar, advised her rest more and come back if the pain did not improve. No one suspected a tumor.

The summer passed and Melissa divorced Chip; her love of change clashed with his comfort with custom. She moved to a small house a short way

down the road. Christopher had daily access to both parents. Melissa remodeled the house. She dismantled and reconstructed a wall in a day, because she thought it was in the wrong place. Next, she insulated and weather-proofed an enclosed porch to make a bedroom for Christopher. She painted a sky on the ceiling so Christopher could sleep beneath the “sun.”

For income, Melissa worked next door at the country store and started her own business: Raivenwood Designs. The name evolved from a wine bottle: Ravenswood Merlot. Melissa added an “i”; she liked the way it looked. She built, painted, and transformed furniture. Her pieces were fanciful: a table covered with small scenes and graceful, spiraling designs; a dry sink adorned with mosaic tiles. She designed and built the sign for a jeweler’s business and restored a four-wheeled horse carriage for her ex-father-in-law.

After two years, life in South Woodstock irritated Melissa. Her ex-husband was too close. A man she met and fell in love with, Jim Johnson, lived down the road with his girlfriend, Susan. It was an uncomfortable situation. To escape the insulated hamlet, Melissa moved. With a newly made acquaintance, Kate O’Neill, she found a large farmhouse to rent in a neighboring village. The sprawling home was ideal for the two single mothers and their children. Christopher had live-in playmates: Kate’s twin boys and infant girl.

Despite nagging discomfort in her neck and back, she bought a lawn mower and weed trimmer to start her own landscaping business. She had a new boyfriend, Scott, to take her mind off of Jim, she had a new house that offered

endless decorating possibilities; Christopher was happy; she was financially secure. It seemed as if the pieces of her life were falling into place.

On September 13, 1997, Melissa tried to sleep and couldn't breathe. Every time her head hit the pillow it felt as if her windpipe collapsed. Changing position was no help. She was being strangled. Scott rushed her to the hospital.

Doctors immediately admitted Melissa to Dartmouth-Hitchcock Medical Center (DHMC). A magnetic resonance image (MRI) was performed. A malignant neoplasm was found in the cervical vertebrae; they found a cancerous tumor in her neck. Eleven days passed. She saw doctors who prodded, examined, and interrogated; she had x-rays, more MRIs, computed tomography (CT) scans, blood tests, bone scans, and biopsies. Sounds from other patients, the beeps and dings of monitors, the chatter from the nurse's station, the caustic smell of disinfectant, and the underlying odor of illness invaded each moment. Every horror Melissa had imagined, every reason she hated hospitals, became her daily reality.

During her stay, she developed swelling in her face and neck, trouble swallowing, more difficulty breathing, and numbness in her fingers. Doctors were puzzled by the tumor; they could not pinpoint what it was or how to treat it. Finally, after a week and a half of relentless procedures, there was a diagnosis. Melissa had Chordoma, an extremely rare cancer that forms from the remnants of cells from the embryonic notochord.

The notochord is a rod-shaped, cartilage-like substance that provides support for our fetal spines. It is an essential building block for the mature spine and the first backbone in every vertebrate creature. In some people the notochord does not completely disintegrate. It is replaced by normal vertebral bone, but the cells of the notochord remain within like potential time bombs. In a very few the notochord remnants begin to mutate and become Chordoma. The three types of Chordoma are sacral, clival and vertebral. The sacral type involves the lowest part of the spine, including your seat bone. The second type is clival, occurring in the topmost region of the spine, the indent at the back of the skull where the neck ends that marks where spine and brain meet. The third type is vertebral. It encompasses the rest of the spine—the neck and back.

As a whole, Chordoma is diagnosed in an average of 300 people a year, accounting for less than one percent of 1,372,910 total cancer diagnoses per year according to the American Cancer Society. The most common sufferer of Chordoma is a male between the ages of 49 and 71. A study headed by Mary L. Mc Master, M.D., *Chordoma: incidence and survival patterns in the United States, 1973-1995*, declared the rate for Chordoma in females as less than six cases per one-hundred-million. That is equivalent to six people out of the entire population of Mexico. For a Melissa to present vertebral Chordoma, odds were higher that she would be struck by lightning. Twice.

On September 24th, 1997, Melissa and two of her closest friends were ushered into a small conference room. Dr. Perry Ball, a tall, sandy-haired

neurosurgeon entered the room carrying a folder of large radiographs. His long slender fingers slapped the MRI images onto a lighted board. Illuminated from behind, recognizable structures appeared: slices of Melissa's neck. Vertebrae stood out—stark white shapes in a sea of shades of dark grey and black. Dr. Ball pointed to where the tumor began. It was a small speck, growing larger with each successive frame until there was virtually no white bone left. Gradually, the white, normal vertebral shape returned just as it disappeared. The images were a terrifying flipbook display.

“Here is why you are having so much trouble swallowing.” Dr. Ball pointed to a particular frame where the tumor had blotted out an entire vertebra. The tumor's image resembled a malevolent Mickey Mouse head, the chin pushing on the small black oval identified as Melissa's trachea. As he pointed to the image, Dr. Ball described the surgery. “The tumor has completely eroded C4 and part of C5.” The fourth and fifth vertebrae are found in the center of the neck. “What we will do is remove those two bones and as much of the cancerous tissue as possible.” He explained that they would build a cage around the spine with bones harvested from a cadaver. Even with the new spine, however, the tumor would return. If Chordoma is encased within bone it can very rarely be removed completely, but if cells have invaded nearby tissues, the removal is infinitely more complicated. Chordoma destroys bone before it invades other tissue and the tissue closest to the notochord besides bone is the spinal cord. In Melissa's case, the tumor was the size of a softball. It had wrapped around her spine, like a

tourniquet. Dr. Ball strongly recommended radiation therapy following surgery; the treatment would enhance her chances of a longer remission; time was the only gift surgery and radiation could offer. The average survival time, from first diagnosis to death, is seven years.

First, however, Melissa had to survive the nine and a half hours of spinal surgery. Dr. Ball and two more neurosurgeons, Dr. Grant Shumaker and Dr. Hulda Magnadottir, performed the intricate procedure. They opened an incision across Melissa's throat. Then the surgeons deepened and widened the cut, through the layers of skin and muscle, until they reached the "prevertebral" space. They exposed the third through the sixth cervical vertebrae, before removing the cauliflower-like tumor and what was left of Melissa's fourth and fifth vertebrae. The missing bones were replaced with a bone graft, held in place by a titanium plate and screws. The replacement bone was a segment of a donated fibula: Melissa's neck was rebuilt using the lower leg bone of a cadaver.

The tumor was so large it had punctured her esophagus. A fourth surgeon, Dr. Gosselein, an ear nose and throat specialist, reconstructed and sutured the damaged area. While the repair healed, she could not swallow or eat. A feeding tube threaded its way through her nose, down the back of her throat, to her stomach. All her nourishment for the next few months, usually a vile, vomit-colored liquid called Jevity, was delivered through the tube. Because she could not swallow, any saliva or mucus had to be spit out. Melissa was provided with a suction hose, the same ones found in a dentist's office. For the first few days of

her recovery the only sounds from Melissa were the squeak of a marker on the white, plastic board and the slurping vacuum.

Her voice was the first thing to return. Melissa's initial request: get her out of the hospital. Hospital protocol required her to stay until the feeding tube could be safely removed. She did not agree. Her mother, Linda, under intense pressure from her daughter, lobbied for Melissa's release. Melissa was discharged. Free from the medical establishment, she gathered friends and family, not for a celebration, but for a moving party. During her long sojourn in the hospital, the lease on the house expired. Directing workers and holding a spit cup, Melissa oversaw her belongings packed into multiple pickup trucks and moved to a new apartment in nearby Pittsford, VT.

She wasted no time in making her new home completely her own. The first order of business was paint. The drab paneling was revived with a warm, creamy color. Bright curtains and pillows were made to lighten the space. She even cleverly inserted a decorative black-iron hook between the dropped ceiling tiles to hang the bag that administered her "food." Melissa did not let spinal surgery slow her down.

Melissa still had to decide whether or not to proceed with the radiation treatment strongly advised by Dr. Ball. There were risks involved. Chordoma requires a high dose of radiation to destroy the malignant cells. Despite the benefits, location of Melissa's tumor elevated the risk of side effects. The radiation could accomplish what the surgery had not in two ways. It could kill any

remaining notochord remnants or destroy her thyroid gland. Melissa weighed her options. As she and Linda painted the new apartment, they discussed the decision. Melissa thought it too risky and unnecessary. Linda agreed. Melissa wanted time to recover and regain control over her life.

In 1998, barely a year after her initial surgery, new growth was detected in the replaced cervical vertebrae. The tumor had invaded the cadaver bones. The news was devastating. She was again encouraged to undergo radiation therapy to kill the new tumor growth. For a year, Melissa had reveled in a sense of immortality; the fact that she had survived the difficult and risky surgery whole, and with no severe or lasting handicaps, only a scar that ran from the center of her neck toward her left ear from where Dr. Ball had slit her throat.

On that late September day, Melissa left the hospital knowing, at twenty-six years-old, with her four-year old child waiting at home, that she was dying. She and a friend left the hospital, drove to a neighborhood bar, and drank a couple of tequila shots. The drinks didn't help. Melissa decided to walk alone by the Ottawaquechee River. Her friend watched and waited. Jim Johnson, the man Melissa had fixated on the moment she had met him four years before, came out of the bar. They had seen each other on and off for months, despite the fact that Jim was still in another committed relationship.

The friend turned to Jim, "She thinks she's dying." The friend pointed to the figure by the river. He was silent. "If you love her, you need to tell her. If you don't, you really need to tell her." After a long pause Jim answered.

“My life is a little complicated right now,” was his quiet response, and he strolled back into the bar.

Melissa followed Dr. Ball’s suggestion. Monday through Friday for four weeks, she traveled to DHMC, changed into a hospital gown and sat, immobile, while a machine blasted rays of radiation at specific points—marked by small, permanent-markered x’s—on her neck.

Although the procedure was a year late, the radiation treatment was successful. It could not guarantee survival, but it bought her precious time.

With her peripatetic spirit and the knowledge that the tumor would grow again, Melissa did not stay put. She broke up with Scott and moved again. This time, she moved in with Jim, the man whose life was previously too complicated to help Melissa through devastation and radiation. Jim lived in a rundown mobile home a long way up a dirt road. The trailer and the man became her biggest projects. Within a year, the trailer was unrecognizable, furnished and decorated. It was transformed from bachelor pad to a cozy home. By the fall foliage season of 2001, she was Jim’s wife. Her dream had come true.

By 2002, however, her freedom from cancer was up. The old pain began to return. This time, it radiated from the center of her back into her neck. Another MRI revealed a second tumor in the seventh Thoracic vertebrae; this tumor had, according to Melissa’s medical report, caused “almost complete obliteration of her cord.” Chordoma is relentless. Any cells remaining in the body mutate. Rarely, it metastasizes, sending seedling tumors along the spine. Melissa

discussed another surgery with Dr. Ball. He cautioned that she had beaten the odds once; a second surgery would have a far higher chance of side effects. He felt there was a good chance a second surgery would, at the least, leave her with permanent weakness or disability in her limbs. The worst-case scenario would leave Melissa a quadriplegic. It was a chance she was determined to take.

The second surgery took four hours. This time the surgeons laid Melissa face down, accessing the tumors from the back. They removed the small pedicle on the right side of the T7 vertebrae and performed a laminectomy on the sixth cervical and eighth thoracic vertebrae. Essentially, Dr. Ball removed a small piece from the right side of one vertebrae, and scraped the tumor from the spinal cord, from Melissa's neck to the middle of her back. When the lesions healed, a radiation oncologist, Dr. Eugen Hug, arranged a second round of radiation. Dr. Hug also investigated possibilities for other treatments, consulting with experts from Massachusetts to Stanford in experimental chemotherapy, Proton Beam, a more thorough type of radiation, and a new surgical technology, the Cyber Knife, a tool that is related to a laser. It allows surgeons to more accurately and completely remove diseased tissue.

From 1998 to 2002, Melissa had nearly four-and-a-half years virtually tumor-free, but when the pain returned, her marriage to Jim began to fall apart. They fought. Jim spent less and less time at home. The damage from the surgeries, weakness and an increasing dependence on pain medication prevented Melissa from working. She went on disability, a difficult transition for an active

young woman. Pain was her worst enemy. The medications to control it were a close second. Every day was a rollercoaster. She would wake up in stiff agony, take her medication, endure the opiate fog, and then enjoy a precious hour or so of painless clarity.

To combat the pain, Melissa's doctors prescribed Methadone—a drug similar to opium and heroin; it works by altering receptors within the brain. Methadone does not block the sensation of pain and it does not act directly against whatever causes pain; it doesn't relieve inflammation or reduce fever the way ibuprofen, aspirin, and acetaminophen can. Like all opiates, Methadone makes the brain forget what pain is; it alters the perception of the experience of pain. Doctors frequently prescribe it to patients who need long-acting, long-term relief. It also causes a laundry list of unpleasant side effects including those that affected Melissa the most: agitation, dizziness, nausea, and vomiting.

Some days, the medication made Melissa manically happy and energetic; the respite from the ache encouraged her to squeeze in as many activities as she possibly could before it returned. She would rearrange furniture, paint, or pick-up Christopher from school and take him for a hike. Other days, she could barely get out of bed. She was snappy and irritated. She yelled and she cried. No one could comfort her. The good days slowly evaporated. The Methadone was not enough.

Rather than accept medical establishment's inability to help her, Melissa turned to Dr. Hug, who recommended Dr. Griffith Harsh. Dr. Harsh was the leading expert on spinal cancers, Proton Beam Therapy, and Cyber Knife surgery.

He was pivotal in the development and use of these technologies to treat Chordoma. Dr. Harsh was the only doctor in the country qualified or willing to perform surgery on Melissa's abused spine. But he practiced in California. Melissa was faced with a choice.

She was tired of fighting this horrible disease; she was tired from the unrelenting pain; she was just plain tired. Six years of her life, two thirds of Christopher's life, had been lived beneath the shadow of terminal cancer. For the first time, Melissa doubted her strength; she doubted her will to fight. Melissa finally believed she might die on the operating table. This was her last chance. The tumor growth was accelerating and relentless. The medication was wearing her down. A long flight would cause unbearable pain. Her courage and drive disappeared. She was terrified.

The deciding factor was Christopher. He faced the loss of his mother. He knew she would never be healthy. At nine years old, he was not sure, if his mother got on a plane to California that she would return. He also saw the alternative. The pain, which increased daily, required more and more medication, which impaired her ability to do the things that made her happy. When the pain was at its worst, Melissa could not care for him. For Christopher, the difficult choice of a mother in pain and a dead mother was no choice at all. He told her she had nothing to lose. He asked her to go.

Once again, surgery was successful. In April of 2003, at Stanford Medical Center, Dr. Harsh removed all of the remaining bone from Melissa's neck. He

built a titanium cage around her spine. Melissa walked away from the operation. Her only lasting handicap was an inability to turn her head or stroll past a metal detector. She flew back to Vermont holding an x-ray of her new “spine” for airline security checks. On a layover, Melissa “slept” through her connection, purposely stranding herself in Las Vegas. She felt too good to let an opportunity to explore “Sin City” pass. She walked the two miles from her hotel to the Vegas strip and spent the day exploring the casinos, indulging in the slot machines. On her way back to her hotel in the dark, an elderly man chided her, warning her that it was not safe for an attractive young woman to walk through the outskirts alone. He found her a cab, paid her fare, and made sure she was safe. When she described that night to her mother, Melissa said simply: “What did I have to lose?”

Illness and the treatment were too much for Jim. He had accompanied Melissa to California, staying by her side for a week, making sure she survived, but upon his return to Vermont, he decided he had had enough. When Melissa came home, momentarily free from the tumor, she found an empty house.

The surgeries had bought precious months; but each operation encouraged the tumor to grow faster. Melissa’s Methadone dose rose from 5mg twice a day to three times per day. It kept increasing until she peaked, taking 60mgs a day; an amount that would kill anyone but the most desperate junkie. She tried to joke about her “heroin” addiction, but the medication was taking its toll. She

experienced withdrawal when she missed a dose. Despite the pain, addiction, and abandonment Melissa pushed herself.

She bought a treadmill and compulsively walked. Her belief: as long as she could walk, she was beating the tumor. Every day for at least ten hours, she marched along. She rigged the treadmill's frame with a wooden shelf and a belt that she wrapped around her torso. Belted in, she read, watched DVDs, knitted scarves and hats, and made jewelry from tiny beads, polished stones and flea market treasures, while pacing out miles. New cards printed for Raivenwood Designs read: "Melissa Patterson. Jewelry, handmade scarves, unique lamps, and custom shades." She sold her creations at craft fairs and local shops, but she gave many away to friends.

Molly, her younger sister, moved in. Melissa's birth-father, Mike Patterson, flew in from California and bought the cabin next door. He wanted to reconnect with his only child. He allowed his daughter free rein in refinishing the interior. It took her a year, but she put down new pine boards for the floor, sanded and whitewashed them on her good days. Of course, she painted the walls, and made curtains and cushions, making the cabin a cozy home for her father's visits.

Winter came. The freezing temperatures and short days were as relentless as the disease. Melissa became depressed, frequently staying in bed, curtains drawn, lights out, huddling with her dogs Oliver and Sarah, and waiting for Jim to return or the tumor to kill her. Melissa was forced to move. The house with its memories of Jim proved as life-threatening as Chordoma.

During Melissa's illness, Linda and Steve had moved from Massachusetts. They bought a house in Springfield, Vermont, a large town almost an hour from Melissa's trailer. Linda encouraged Melissa to move. Mike stepped in, put his cabin up for sale, and purchased a house three blocks from Steve and Linda. The new house was on a tiny cul-de-sac. It had a small grassy-lawn and an in-ground pool. Inside, there were plenty of rooms; Michael and Melissa could each have their own private spaces.

Melissa began to thrive again. The town had a long bike path. Melissa would walk down the hill from her home and along the path, carrying a book and her small Toy Fox Terrier, Oliver, in a sling across her chest. When summer arrived, she floated in the pool. The water relieved the pressure on her spine, offering relief from the ever-growing tumor.

On October 3, 2005, a day past the monumental seven-year anniversary of the first surgery, Melissa was back at DHMC. While attending the funeral of an uncle, she developed weakness in her right leg. Unable to raise it, she was forced to drag it along. An MRI showed marked growth of the tumor. She consulted with both Dr. Ball and Dr. Hug. With Linda present, Melissa received the news that there was nothing more to be done. Dr. Hug wrote in his notes the results of the meeting: "It was the summary of this discussion that basically, at this point in time, neither surgery nor radiation treatment has anything significant to offer." It was clear, that while expected, the news was difficult for all involved, even her doctors. Dr. Hug, who referred to Melissa in all of his notes as a "delightful young

woman” frequently saw her without an appointment, even though she was no longer his patient. Melissa was referred to a palliative care physician and admitted into hospice.

Besides the loss of function in her legs, Melissa and her mother had begun a routine that highlighted the growth of the tumor. Every morning at six, Linda arrived to help her daughter out of bed—Melissa had purchased a memory-foam adjustable mattress to sleep comfortably. The process began with Linda pushing the button to raise her daughter’s head. Linda described the ordeal.

“I would put the bed up a tiny bit. Melissa would wince; we’d have to go back down sometimes two or three times. We’d lift and wait for the tumor to settle into place, then lift again, wait, lift. It was so hard to watch—just incrementally rising, so the tumor could get comfortable.” The growth was now attached only to the spine; it hung there, pulling on the cord whenever Melissa changed position. “I was amazed at how much pain she could take,” Linda continued. “Here was the daughter that called me before Christopher was born because she was afraid of the pain of childbirth. And now, she was dealing with, had been dealing with, so much pain for so long. It was so much worse than having a baby. But she was so determined to live.”

The first treatment offered by the hospice physician was a course of high-dose steroids. The treatment would reduce the inflammation caused by the tumor and increase Melissa’s mobility. That was the golden word: mobility. Melissa’s greatest fear, that which pushed her to walk for hours a day, was being unable to

move. She began taking Decadron, a steroid generically known as Dexamethasone.

One day Melissa grabbed her dog and decided to walk to her mother's house. It was a stroll of only three-tenths of a mile, three large blocks. A few weeks before, Melissa had been walking five miles a day. Linda saw her daughter from the kitchen window and watched the struggle. Linda offered no help. Melissa needed to win this small fight against the tumor. It took most of an hour, but Melissa arrived, exhausted and beaten. Chordoma was winning the war.

Steroids cause weight gain, water retention, and swelling. Melissa became a bloated caricature of herself. Fluid pooled into the legs that used to pace out numerous miles, transforming them into pillars of overstretched skin and open sores, adding a new dimension to her bodily pains. Melissa could walk, but felt that the steroids made her "crazy, unable to sleep and not in her body." She regulated her doses and tried to find a balance between pain and craziness. Between the effects of the Methadone and the Decadron, it was a monumental task.

To escape the discomfort of the swelling, Melissa devised a plan. She sat in her recliner for hours each day, legs elevated and wrapped in thick bandages. In characteristic fashion, Melissa added an unusual twist to the treatment. Before the bandages were wrapped around her fissured skin, the fabric was soaked in peanut oil. The sopping rags were wound carefully around the tender skin.

The bandaging defied medical logic. The steroids impaired her body's ability to heal open sores. Salves and moisturizers were fine. Wrapping and soaking the sores, depriving them of air, and drowning them with bacteria laden cloth, was not. Nevertheless, that was what Melissa wanted. If her helpers wouldn't do it, she would. Molly was unwilling to let her sister hurt herself, so she complied. Molly knew that when Melissa expressed a wish for everyone to get along, it frequently meant: "Do it my way and we'll all be happy."

Melissa continued to suffer. The steroids caused tooth decay, hair loss, and abdominal weight gain. They drove her crazy. She became severely hyperglycemic; her blood glucose level was nearly six times normal, a life-threatening amount of sugar in her blood. Her brain function was impaired. She lashed out at her caretakers. When they forced her back in the hospital in July of 2006, Melissa talked a friend into reporting her mother and stepfather to social services. She labeled Steve and Linda toxic, refusing to speak to them. Melissa was angry that no one would help her. She felt trapped. She had lost control of her life. The price of limited mobility rose too high. Her team of hospice doctors decided to wean her off steroids and allow her to return home.

She could no longer walk without the help of a walker. Survival was now measured in months; she wanted to be alive for Christmas, the New Year, and then Christopher's birthday. Medications increased. Melissa kept fighting. She celebrated the start of 2006 able to sit up and occasionally stand or walk a few steps. Her world diminished rapidly from the house, to the first floor, to a large

sitting room. She was provided with a “potty chair” so she would not have to be wheeled or carried to the bathroom. Then, when the chair proved too arduous, a catheter was placed so she would not have to get up.

The pain was constant. Even being lifted into the recliner was not worth the accompanying surge of pain. The bed became Melissa’s world, constantly adjusted up or down to counteract the tumor’s pressure. Her muscles weakened and atrophied. When she lost the strength to push the bed’s control buttons, she ordered others to do it for her. Friends and family members rotated duties. Melissa was never alone; she needed to be fed, offered water with a straw, covered, uncovered, moved slightly, massaged, and comforted. Her one remaining small joy was smoking. Upon demand, someone would hold a stick attached to a clothespin, which held the lit cigarette to Melissa’s eager lips. “It’s not like I have to worry about lung cancer,” she would retort to anyone who questioned.

By the end of August, 2006, it was evident that Melissa could no longer be cared for at home. The pain was too intense, the amount of daily care was overwhelming, and everyone close to Melissa was exhausted, emotionally and physically empty. The decision was made for Melissa to be admitted to the Hospice House of Concord, NH. The facility was nearly two hours from their home, but Linda, Steve, Mike, Molly, Melissa’s youngest sister Heather, Chip, and Christopher, made the trip daily, often spending the night. Jim never made the trip.

On Tuesday, September 19, 2006, Melissa called her closest friends and family together to say goodbye. She had made a decision to be placed under heavy sedation to avoid the pain. She hoped to finally “go to sleep and not wake up.” The next day, the attending physician administered the medication. The treatment did not work; Melissa stayed conscious. Due to the increasingly huge doses of opiates used in recent years to simply control her pain, her resistance to medication kept her aware and awake. Frustrated and helpless, she sent her family home and waited for sleep.

Two days later, Melissa was with one of the hospice nurses, who read aloud by Melissa’s bedside. The entire family had gone home to rest. Melissa halted the recitation. “I think I’m dying,” she said and sent the nurse to call her mother and Steve, her father, and Christopher. Those called by the nurse had lived beneath the shadow of the disease for nearly a decade. They had ridden a rollercoaster of near death and survival for months. It was a two-hour drive.

Melissa’s voice had been full of wonder. “I think I’m dying.” And before anyone arrived, she did.

“It makes me sad.” Linda’s voice rasped with years of smoking, a savored vice. “Melissa was such a force. She could be difficult, to say the least. She was a Gemini, you couldn’t get around that. You had to deal with both sides of her

personality. And,” Linda’s blue eyes lit up, “ya never knew what you were gonna get.”

“Melissa was here to teach us something about ourselves,” Steve declared. He wore wire-rimmed glasses and a baseball cap over his short, grey hair as he remembered Melissa. While not a large man, when he spoke, the conviction and strength in his voice commanded attention.

Linda laughed. “Well, she sure taught me a lot. She was stubborn, but maybe that helped her survive.”

“Her Taurus moon,” Steve added.

Linda nodded, smiling as she remembered, “She had a way of challenging you, bringing out the best in yourself. Melissa had a clear vision of what ‘could be,’ the possibility in everything.”

Steve explained it. “Whatever happened the day before was irrelevant. It was a source of enormous frustration for all that loved her.”

“Yes,” Linda nodded.

“But she could never build on things. It was all new. She never understood what the past was.” Melissa never looked back.

Two years after his daughter’s death, Michael Patterson paced the kitchen and brewed chamomile tea. He served the steaming liquid from a black teapot into orange and green mugs that he picked from a shelf of yellow and teal counterparts. The room remained as it had been during Melissa’s illness. An open

unit of shelves held glasses, mugs and dishes. Most were a Fiesta-ware knockoff set of yellow, orange, blue, green and teal. Behind the plates rested a large platter. A red horse, its flame-colored mane blazing, galloping on a field of dark blue; a piece of art mixed with dinnerware, a telling remnant of the woman who lived here. Mike leaned on the island-like table. Its dark finish and heavy presence anchored the room. Melissa built it.

“Having known Melissa helps me get through my life,” he said. “She used to tell me to find one thing that made me happy. Find that one thing and do it. That keeps me in this house. It keeps me going. Even if it is making a cup of coffee, or a cup of tea, it motivates me.”

He made slight changes to the house, but the majority of Melissa’s things stayed as she left them. Even though he felt a pull to return to Sacramento, Melissa’s memory kept him here.

“I know I should start to get rid of some things. I should look into getting rid of that.” He pointed to the large bed that remained in the other half of the large room. Almost apologetically, he continued, “There’s so much of her here, I don’t really notice most of it anymore.”

The sitting room was quiet. The smell of sage and cigarettes had dissipated. In a corner of the room, wire cubes stacked four high and four wide were laden with Melissa’s craft supplies: a starfish, collections of beads and wire, paints and brushes, jumbled within the boxes. The floor lamp in the corner,

crafted by Melissa with twigs and parchment, cast long shadows on the café-au-lait walls.

Collages of pictures arranged on poster board are a few of Mike's contributions to the house. Each picture was filled with meaning and memory: a chronicle of Melissa's life before cancer. One photo showed Melissa in profile, sitting on a hillside with her ginger-colored dog Sarah, valleys and mountains in the distance blurred, the woman and dog, vivid against the view—an image of Melissa at peace.

CONCLUSION

I was recently asked, “Would you have written this if they were still alive?” The answer is, yes, but also no. For Melissa, death loomed from the moment following her diagnosis. She wanted to write her own story, her autobiography; she wanted to chronicle how she beat Chordoma. I knew that her death passed that task onto me. I was her backup plan.

I never expected to write about my mother or my aunt after their deaths. There were simply too many unanswered questions that I had hoped to ask. My mother and I had discussed writing her biography. More than one person had approached her, inquiring into why and how she remained employable into her seventies; at Melissa’s funeral one woman broached the possibility of filming a documentary about my mother’s experiences. And Snooker should have written her memoirs. Although we shared a close bond, especially since her retirement, there was a great deal Snooker kept buried. As her oldest friend, Lynne Englebreath remarked, “Everyone knew Snooker and many felt close to her, but Snooker only let people in so far.”

What I found in this journey was that I was fortunate to know them. Individually, each possessed the inner strength to embrace their true selves. Melissa used her creativity, against the ugliness of Chordoma, to beautify her world. She never stopped fighting to survive on her own terms. My mother

believed whole-heartedly in the phrase, “there’s no such thing as can’t.” Quitting was not an option. And Snooker fully embraced being Snooker despite speculation or ridicule; she could laugh at herself or transform into the consummate professional without compromising her core persona. They shared an ability to surpass the limitations society placed upon their shoulders with assurance and persistence; not one of them considered “no” an acceptable answer.

The research and remembrances required to write these profiles have brought me closer to recognizing my own strengths. I have a deeper appreciation for those uncommon people who daily influence my life. What was, in other circumstances, an unremarkable photograph became symbolic; accident and hindsight made it so much more. These three women inspired many, but were connected through me; I was the beneficiary of their combined contributions. Through their stories, I discovered my own.

APPENDIX

The women in the picture from right to left: Snooker, Betty Ann, Melissa.



Eulogy for Mom and Snooker

It's amazing that one family could produce two such strong and unique women. First, there was my mom, Bettyann. Then, seven years later Snooker came along. Snooker told me repeatedly that my mom was the best sister anyone could have had.

For my sister and I, mom was always a role model. Strong, driven, and unwilling to let anything or anyone stand in the way of what needed to be done. We wanted to please her, but she set the bar high.

Overcoming the repercussions of a terrible accident when she was in high school, my mom turned her natural drive into an unstoppable force. Her favorite response to teenage whining sums it up: "There's no such thing as can't". Throughout our lives, even when we couldn't fully appreciate her achievements, my sister and I knew she was doing incredible things.

She was the strength and motivation for our family, the protector and provider. The Queen.

Snooker was both the court jester and archivist.

Through both of them I was able to see the country. With Snooker there was her beloved Hawaii. When I was eight, I was there for one glorious summer and then our road trip when I was 10, which took us from Denver to LA with so many stops in between.

My mother showed us parts of Texas, Arizona, Colorado and Ohio we had never heard of- not the tourist places but, she'd always try to show us something- even if it sometimes involved 2 or 3 carsick, crowded and bickering hours. And she allowed me the opportunity to spend a glorious month in Prague- something I'd never dreamed I'd actually do.

When each moved to Vermont my world was altered completely.

First Snooker arrived. And in the past 11 years I have had her present in my life- not just a random phone call (This is your auntie Snooker) or at various holidays and family events. She was here. And now weekends were gardening and shopping trips for plants in the summer and craft supplies or books in the winter. Just recently, I had finally figured out how to get her out of Wal-mart or Ocean State Job Lots in less than 2 hours.

My mom only begun to adjust to Vermont and we were beginning to work out our schedule. I was learning that a trip to the dump was now a joint effort, and that while she was "perfectly capable of doing this on her own since she had lived by herself for the past 14 years, she would go grocery shopping with me if I wanted".

There were times in the past six months when I would feel like a ping-pong ball caught between those two and outings with them were lessons in listening (To 2 conversations and opinions at once) and patience (they would pause to let me answer sometimes).

But my mother gave me support and allowed me to live with the horses and the farm. She allowed me to go to school and she pushed when I was unsure. And Snooker would have given me the shirt off her back- thank god she didn't have to because she had 4 brand new ones with tags in a drawer-“ it's a men's x-large in orange and pink stripes, but you can wear it in the barn.” And she has given Anne a new lifelong hobby on E-bay. I'm sure there is someone who wants 10 boxes of various seedpods, pinecones, and waxed leaves.

They leave a tremendous hole in my family's life. They were vibrant, so full of energy and life- not little old ladies slowing down, but forces of nature. We will never fill this hole. We will have to learn to work and live around it. But whenever it becomes too much, or a task seems insurmountable, their legacy will be there. Because Snooker left us plenty to do and as my mother always believed- there is no such thing as “can't”.

Eulogy for Melissa

Melissa moved with the grace of assurance. I remember her as a young woman glowing with the echo of California sun. She was tall, blonde, lean, fit and confident. I hated her on the spot. She fixed her own car and lived in a cabin with no running water. She washed her hair in the tack room sink and subsisted through the day eating nothing more than an apple. I envied her lithe dancer's build, the easy smile, and her fearlessness.

But somehow, we worked well together, taking care of the horses, for all of our other differences, completely on the same page. We had a system, it was something we simply fell into, instinctively knowing what the other was doing and getting the job done. I don't know when we became friends exactly, we just did, and her friendship was one of the most significant gifts of my life.

Melissa was my best friend, the keeper of all of my secrets- she knew me better than anyone - including myself. She accepted who I was, knowing all that I was, and taught me to do the same for myself. There were so many lessons: that it was OK to say no, to nurture myself, accept what was freely given, and not to take myself too seriously. Most importantly she taught me to forget the word impossible, because Melissa moved through the world with a carelessness that dared anyone or anything to stop her. If she put her mind to it- decided something needed to be done- it was.

Even in the face of horrible disease, she lived life on her own terms. When our lives began to parallel in ways we could have never foreseen, we never had to explain or justify whatever the other was thinking- we knew.

Was she perfect? No. At times those qualities that inspired me, annoyed me to tears. And yet, that is what made her interesting, made her uniquely Melissa. She was not with us long enough, and pain and disability colored much of that time. But she was here and the legacy she left will continue to touch and shape my life. Because she was my friend I will continue to reach for the impossible, forget the word can't, and live my life on my own terms.

She was one of those rare people who changed all that she touched- even the most mundane things became art- became beautiful. She touched me and she will be in my heart forever.