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time with her and showed her our legal documents. She reviewed his completed Health Directive, the Alzheimer's Disease/Dementia Advance Mental Health Directive. These were forms from End of Life Washington. I also showed the social worker Thaddeus Pope's long white paper and the reference he made to voluntary stopping eating and drinking. Also, I showed her the Release and Assumption of Risk form that our elder care attorney had prepared. It was witnessed and notarized at our house three days before Alan began the VSED process. The social worker wrote a positive report about her visit to our house, and the case was closed.

On the fourth and fifth days of Alan's fast, he asked me for water. Both times, I reminded him that he wasn't eating and drinking so he could avoid living into the late stages of Alzheimer's disease. Then I said, "Would you like me to give you a glass of water, or can I spray your mouth with mists of water until you are relieved?" Both times, he replied, "Just use the mists of water."

When Alan could no longer open his eyes, I said, "Alan, I am here with you. If you are comfortable, blink your eyes." He was able to do that. I knew he was okay and not suffering. Our doctor stayed one step ahead of him and gave him appropriate medication to keep him physically comfortable. I didn't want him to suffer at all.

Alan was saying "YES" to life, up to his last breath, on his terms. His death was peaceful and completely in rhythm with how a body dies. It was a deeply considered, conscious decision based on self-love, peace and compassion. Alan's plan and decision was not secretive, but shared with many who loved him. He died with me by his side, talking lovingly to him, helping to midwife him toward the mystery of death. He was grateful for the good life he had lived and to have the choice to VSED.

After Alan died, many people came forward and expressed what a profound effect his choice had on them. People perceived his actions as loving and courageous, as a demonstration of his civil rights. They saw dignity in his death. Some felt deep relief knowing that this option is available to them in the future if necessary.

We are all going to die. VSED is one way of expanding our choices about how and when we

die. My husband made a courageous and loving choice. If necessary, I'm grateful that I also have that choice.

I miss my husband very much. But I'm glad I was able to support him through the choice he made to VSED. He had a good death. My support of my husband, through his process of dying peacefully and consciously, was my biggest act of love.

Perhaps Alan's biggest act of love toward me was his showing me how a person can die peacefully by choice, with dignity, even in the face of horrible disease. I am no longer as afraid of dying, and I feel my husband is in my heart and with me all the time.



## Life and Death on Her Own Terms

Susan Schaffer with Elliott Schaffer  
and Janet Malek

At 87-years-old, my mother, Beatrice, appeared to be in excellent health. The matriarch of a family of three daughters, she had continued living a full life after being widowed in her mid-50s. She started a new career as a travel agent, served actively on community boards, lent a hand with her six grandchildren whenever she could and enjoyed the theater and orchestra. She traveled the world in her own unique style, rejecting group tours in favor of driving around the countryside with her traveling buddy like an elderly (but law-abiding) Thelma and Louise, until she was well into her 80s. Only two years before she had moved into an independent apartment, which was part of a continuing care retirement community and she was enjoying a rich social life there with many new friends. Mom was a source of wisdom in a quiet, commonsense way and yet, remarkably, she remained completely open to learning from others. She was ageless, fitting into any group, not as an elderly parent to be humored, but as a contemporary who was interested in others, happy to meet new people and have new experiences.

And so in January 2009, when Mom suddenly began reporting vague aches and pains and her typically sharp reasoning became somewhat fuzzy, we were concerned. We began the search, through a series of medical appointments, to determine the cause of her uncharacteristic behavior and sudden signs that she was slipping, both physically and mentally. In April, she was diagnosed with squamous cell cancer of the mouth. There was a tumor growing in her jawbone.

After much discussion taking into account Mom's active life, the things that were important to her, and her blood tests, Mom and her oncology team agreed that antibody therapy with concurrent radiation treatment was a reasonable option. Mom was realistic. She knew the treatment might not work, but she "had to give it a try."

Initially Mom insisted on driving herself to radiation treatments but after several weeks we felt that her growing fatigue was becoming a safety concern, so one of us or an aide, would take her to her appointments. After two difficult months of radiation and chemo, the treatments ended on her 88<sup>th</sup> birthday. We all looked forward to Mom's regaining her strength and her humor, but she didn't rebound as quickly as we had hoped. Her fatigue persisted and she wasn't able to reengage with the people she loved and activities she enjoyed. In addition, the radiation therapy had significantly affected her mouth and she could no longer eat solid food. She lived on liquid dietary supplements, which she had to be coaxed to finish.

After Labor Day, we learned that the treatments had not worked; the cancer had spread and her life expectancy was now measured in months. It was the only time throughout the ordeal that I saw Mom cry. She told me that she was not afraid to die, but she dreaded the pain and debilitation to come in the final stages of her disease. She wanted to be in control of her life and her death rather than suffering as a victim of her cancer.

Mom's affect at this time was marked by depression and hopelessness, which was not characteristic of her personality. Consuming the liquid supplements was a burden for her. She would take one or two sips and the rest of the glass would sit on the

table until it was time to open another, unless we persuaded her to drink the remainder. Her nutrition had become a source of tension and conflict, which we didn't want to be part of our remaining time with her. Mom began thinking about whether she could just stop eating, but feared that would be just as painful as dying from her disease. Meanwhile the tumor was visibly growing, threatening to occlude her windpipe and causing significant pain. Mom was not accustomed to taking medication and was particularly resistant to the idea of narcotics, creating another source of conflict. Seeing her in such pain was difficult for all of us.

I felt torn, wanting to hang onto every remaining minute of her time with us, but understanding her perspective. I suggested that she discuss her options with my husband, Elliott, a family doctor and geriatrician. Elliott had a vague memory from medical school of a nutrition lecture in which it was mentioned that starvation is not a painful way to die, due to the development of ketones in the blood, which suppresses the feeling of hunger. Elliott and I searched the internet for information about whether cessation of nutrition and hydration was a reasonable way to hasten death, and we found that there were a few reports in medical journals of people using voluntary stopping of eating and drinking (VSED) to accomplish that goal without increased suffering.

Mom and Elliott had a long talk during which Elliott shared the information that we had found about people who forgo food and water in order to hasten death—that they do not experience increased pain or significant hunger after the first day or two and generally have a peaceful death with little or no suffering. Mom decided that this was the course she wanted to take, but she was not ready to stop taking nourishment just yet. There was an immediate and dramatic change the day after Mom made her choice, even before she implemented it. She was clearly less depressed and more engaged. It was as if she realized that she no longer had to worry about what was to come. She had taken control—and she found comfort in that.

Once Mom's closest friends and family heard about her prognosis, they all arranged to visit her.

She quietly and individually spent time with her brother, her daughters, and each of her six grandchildren and their significant others. She smiled as her great-grandsons rolled around on her bed. The morning after the visit with the last of her grandchildren, Mom refused her liquid supplement, quietly informing us that she had decided to start her fast, effective immediately.

Her choice itself was not a surprise, but the timing was a shock. We scrambled to put things in place at Mom's apartment. Although we had engaged hospice, the nurses and aides were not familiar with death through voluntary stopping of eating and drinking. They encouraged her to "wean herself gradually" off of food and fluid, which we knew from our research would lead to a prolonged feeling of hunger and thirst. The articles stressed that both food and water needed to be eliminated completely to allow the development of the ketosis necessary to eliminate these sensations. They also mentioned that ketosis often leads to a feeling of mild euphoria, which also contributes to making the fast tolerable. Fortunately Elliott was able to share our research with the hospice nurses who thereafter did not become an obstacle to Mom's goal.

My sisters and I arranged for someone to be with Mom at all times, expecting her strength to fail precipitously. Each morning, I would drive to her development, park the car, and mount the stairway with trepidation, all the while wondering how much closer to death Mom had traveled overnight. Amazingly, I found that each day Mom's spirits grew lighter and more peaceful. She did not complain of hunger or thirst. The stream of friends and family continued, and Mom would doze lightly between visits. The rabbi came to visit and returned each day thereafter, commenting about how much he was learning from her about death and dying. At first we thought we should protect her from so many visitors—that it would tire her too much—but then we asked ourselves, "Protect her for what?" She clearly enjoyed the visits, and was unfailingly cheerful and nostalgic about her experiences and relationships. She was also open to discussing her decision to fast, which almost everyone found somewhat shocking.

We talked about death; she was clearly not afraid of dying. Mom expressed curiosity about what she would experience after death and whether she would see her parents or our dad, but then quickly dismissed her curiosity with a peaceful acceptance of her fate. I wrote a draft of her obituary and she helped me edit it, correcting inaccuracies and including the experiences most important to her. She frequently smiled, reminisced and acknowledged what a good life she had lived.

At the end of the first week of her fast, Mom was still so comfortable that she wondered out loud, "When is something going to happen?" We assured her that it generally takes no more than two weeks for a body to slip away without food and water. Mom continued to deny feeling any hunger. At one point she asked for a cup of coffee and we wondered if she had changed her mind about the fast. We scrambled to make her a cup of decaf after which she took a few sips and declared it to be "the best coffee I have ever tasted." But she never asked for more. She also expressed appreciation for the few sips of water that she took with her pain medication; we soothed her dry mouth with a spray that helped replace saliva, and that seemed to satisfy her. The first week she got in and out of bed herself to use the bathroom but after that used the bedside commode with assistance. Gradually in the second week she became confined to bed. The hospice aide gave her daily massages with lotion, which she enjoyed enormously, although she had never been a fan of massages during her lifetime.

At no time did Mom appear to be suffering. She lived those last days with a tremendous grace that touched everyone who was privileged to spend time with her. By the end of the first week Mom was sleeping more but when visitors came she was easily aroused and happily engaged in conversation. At day nine or ten of her fast, she became more lethargic and her conversation became less clear. And yet her perception and self-awareness were still sharp; she commented with mild frustration, "I know I am not making sense." We continued to be at her bedside, treasuring her company and knowing she found comfort in our presence.

On Day 11, Mom became less responsive. On Day 12 she peacefully slipped away.

Mom taught us so much during her lifetime, at her life's end, and particularly in those last 12 days. Witnessing her poise, her humor, her wisdom, and her compassion for all whom she touched in the extraordinary circumstance of her passing was an experience that I will never forget. Seeing her take control of her death, much as she had of her life, was empowering to everyone who was with her and who heard of the circumstances of her death. We are so lucky to have had her in our lives.



### **Sarah's Second Attempt to Stop Eating and Drinking: Success at Last**

Judith K Schwarz

Sarah was an 81-year-old widow who had been living independently for seven years when she pushed her life-line button for the last time. This was the second time she had fallen that morning and had to call for help because she could not get up. The first time the EMTs arrived, they helped her up and into a chair and left. The second time however, despite her strong objections, they transported her to the local hospital where it soon became apparent that she had suffered a serious stroke. Her daughter Laura rushed to her bedside, and as Laura waited to speak with the neurologist, she reviewed in her own mind her mother's medical experiences.

Sarah had been a life-long member of a "right to die" organization, and was adamant that she would never agree to be in a nursing home. Her husband had died of Alzheimer's disease the previous year after spending the last five years of his life in a nursing home as his dementia progressed. Sarah found the nursing home atmosphere so awful that she visited infrequently. She lived a life of happy independence in her sunny apartment with its prominently displayed grand piano that

she played each day with great passion and skill. She had friends in the neighborhood, played Mah-jong regularly, and kept in touch with other friends and family members by e-mail. She loved to read, listened to music all the time, and was very aware of current events as she read a daily newspaper on her computer.

But things had begun to deteriorate over the past year. Laura counted up the number of falls that required hospitalization and treatment for broken bones. Sarah had broken both shoulders and several ribs that left her with diminished upper body strength. She was impatient with the recommended physical therapy and often stopped too soon—with the result that she could no longer get up from the floor when she fell—accidents that now happened regularly. When Laura met with her mother's physicians, they confirmed that she had experienced a stroke that left her paralyzed on the right side of her body—her dominant side—although she appeared cognitively unaffected. The doctors also thought that she had suffered a series of 'mini strokes' in the past—hence all those falls.

Sarah remained in the hospital for a week before being transferred to a well-regarded rehabilitation facility in the area. Laura visited every day and was initially pleased to see that her mother willingly participated in the rigorous physical therapy—three times a day and twice on Saturdays. While not much could be done with the muscles on her injured right side, she clearly was developing muscle strength on her non-affected left side—strength that would be necessary if she was to successfully 'transfer' from bed to wheelchair. The rehab clinicians anticipated that Sarah would be with them for three months and then 'transition' to an 'extended care' facility. However, that was not to be.

Despite the excellence of the care, Sarah found it intolerable that she needed assistance with all aspects of daily living. She had always been a private person, and to have to ask (and often wait) for assistance with toileting and personal care became increasingly humiliating and frustrating for her. Each day she would tell Laura that she "wanted out of rehab and out of life" and she wanted her daughter to help. Laura was not surprised by her