

# SMILE!



Elizabeth Walton Roberson

## *Even Her Deadly Slow Journey Through the Managed-Care System Couldn't Quench My Mother's Thirst for Life*

By Allison Acken, Ph.D.

**W**hen my mother reached the age of 85 and was still perfectly healthy—working and walking five miles a day—I began to think that she might live forever. One year later, it was a shock to hear her doctor diagnose "... melanoma, metastasized to one of the lymph nodes in the neck." Reality struck hard. My thoughts raced. "How will I get her through this?" "How will I get through this?" "How will I tell the kids?" Not only would she not live forever, she will die within a very few months.

My mother is approaching her death the same way she lived—with silent courage and

a determination to have a good time. It was strange how calmly she took the news. This woman, who had been a bit of a hypochondriac for most of her life, simply nodded and said, "It isn't in my brain, is it? I don't want to be a burden."

Over the next few weeks, I kept waiting for the breakdown that never occurred—at least not in front of me. Insisting that we tell no one, she said, "People treat you differently if they know you're sick. I want people to treat me just the same." Those of us who did know were falling apart with each other, but she continued to laugh and party as

The author's mother, posing in front of the store she managed in Baltimore in the '40s.

usual. The way she faced her diagnosis made me appreciate all that she had taught me about life and money—and what she would now teach me about dying.

### **What Mom Knew Best**

**Live it up!** That was her motto, and she did. Elizabeth Walton Roberson loved fun and good food (as long as someone else cooked it). She raised us as a single mom, yet still managed to take us to restaurants, plays, movies, and amusement parks. We played cards, spent days at the shore in the summertime, and lived like we hadn't a care in the world.

### **When you have a windfall, share it.**

Once or twice a year, we would go to Pimlico Racetrack in Baltimore—my mother, her best friend Mary, my brother, and me. Whoever bet on the winning horse supplied the cash for the losers to continue betting. (Mind you, we were kids; the adults had to bet for us.) At the end of the day, the person who won the most money bought dinner for everyone.

**Work at something you love.** Mother was a great saleswoman, no matter what she was selling. When we lived in Baltimore, it was records, then record players, then television sets. Later, when she joined me in California, she ran one of the country's last department-store book departments. Here she catered to movie stars and became their best source for a good read. People lined up around the block for her celebrity book signings. She loved contact with people and always made work fun.

**Take good care of your family and friends.** She must have told me a million times that nothing was as important as family and friends. Her friendships were strong and long-lasting. She was always ready to go, or ready to help out. When her brother, Jack, had financial problems, Mother got a loan (somehow or other) to help him until he could get on his feet again. When I told my cousins, Uncle Jack's girls, that their Aunt



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Elizabeth was sick, they got on the next plane to Los Angeles from Baltimore. They ordered dozens of steamed crabs to be flown in for her last crab feast.

### **Money doesn't make you happy.**

Notice that none of the above lessons are about saving, investing, buying property, or accumulating wealth. She spent every penny she earned and didn't know the first thing about money management. She didn't have a checking account until she was 70 and never did get the hang of balancing that checkbook. When she was 75 or so, she started saving a little; somehow it finally struck her as a good idea. She did no estate planning, because there was no estate. Now, in her last months, we are handling the few details well. My mother added me to her accounts. She updated her advanced health



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*Celebrating with son Tugger at the author's wedding.*

directive and was very clear about her wishes. She told me where all of her important papers were. We were very lucky to have such a smooth path; so many families shut down when the matriarch is dying.

**Smile.** One of her favorite songs was "Smile (Though Your Heart Is Breaking)." She had always been a "party girl," but her life was not easy. Her husband was a psychiatric casualty of World War II who abandoned her. Her son, my only sibling, was diagnosed with Hodgkin's disease when he was 15 years old and was given only 18 months to live. She told no one on the theory that he would live longer if he didn't know. Tugger lived for five more years. Between treatments, he traveled, played pool with Minnesota Fats (really!), and learned to play golf before he became too weak to keep it up. I will never know how she managed to smile through those years.

**The doctor isn't always right.** Most of her life, she believed in the infallibility of doctors. However, a few months after her belated diagnosis, she asked that I write about her experience in the hopes that "it could help someone else." She was referring to her battles with the health-care system. A prudent financial decision made 10 years earlier proved to be a poor medical one: When she needed treatment, her choices were limited by the constraints of her HMO.

### **My Mother Versus the Managed-Care System**

Ten years earlier, Mother had been confronted with an unexpected crisis about her health-care coverage. Henshey's, a grand old department store in Santa Monica, where she had worked for 20 years, closed abruptly, after sustaining irreparable damage in the 1994 earthquake. The store had been covering the cost of her Medicare supplement, and now that it was shut down, she was on her own. The supplemental premium was too high for her to manage.

Unfortunately, at that point, I was struggling to pay for educations and weddings, so I was unable to help her. In hindsight's clarity, we should have found a way. A friend suggested that she sign up for a more affordable managed-care plan; she'd be on Medicare but there would be no supplemental premium and all costs would be covered. It sounded great to her, and it was—as long as she remained healthy. Once she became ill, however, the flaws in her HMO coverage became all too apparent: long waits for appointments, bureaucratic paperwork, and limited choices.

Last year, she began to have some problems with her balance, which came on fairly suddenly. She was afraid of falling but adamantly refused to use a cane or walker. My younger daughter and I went to the

## **WHAT YOU NEED TO KNOW ABOUT MEDICARE**

**T**his national health insurance covers everyone age 65 or older who pays Social Security taxes or is eligible for Social Security or Railroad Retirement benefits. Medicare is divided into two parts. Part A is free of charge and pays for hospital stays and care in a skilled nursing home as part of after-hospital care. Part B covers physicians' fees and outpatient services at a hospital, as well as certain medical services and supplies. It costs a small monthly fee and pays for 80 percent of reasonable medical costs. You are responsible for paying the balance, which is why many people opt for "Part C" or supplemental private health insurance plans.

It is recommended that you buy this "medigap" insurance in the first six months after you begin coverage under Medicare Part B. During this time, insurance companies are required by law to sell you any policy available in your area. If you wait to purchase a supplemental policy until you have a major health problem, you may find it difficult to purchase affordable coverage.

You must register for Medicare, even if you decide not to take Social Security benefits at age 65. Apply up to three months before your 65th birthday and your coverage will begin as soon as you reach 65. Any delay beyond that window of opportunity pushes back the date at which your coverage will start. Enrollment periods run from January 1 to March 1 every year, with coverage beginning in July.

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*'We cycled from appointment, to test, to appointment, to test—all with weeks wasted in between. The HMO would approve only one very specific scan at a time, an example of the penny-wise, pound-foolish mentality of the HMO system,' says the author.*

doctor with her because her symptoms were worsening. We were all worried. There was no evidence of a stroke or any head trauma to account for her trouble walking.

Firmly convinced that she had Parkinson's, her physician referred her to a neurologist. Knowing how long we'd have to wait to get approval for the referral, we asked



*With Cesar Romero at a fundraiser in Beverly Hills.*

whether we should switch out of the HMO to regular Medicare coverage and then purchase a supplemental policy through AARP. The doctor said that doing so would certainly make his life easier; he could then send her immediately to specialists and wouldn't be limited to the doctors on the plan. We

agreed to look into it, I went back to work, and my daughter took Mother directly to the

medical supply store and bought her a top-of-the-line walker.

**(Tip: When you can't get your mother to do something you think is necessary, ask your adult children to talk her into it. It works!)**

If I could change one thing, it would be the next decision we made. Mother was adamant that she did not want me to take on the extra expense of the supplemental policy the doctor had recommended (a few hundred dollars per month). She put her foot down, saying that her HMO coverage was perfectly fine. She let money stand in the way of good health care, and I didn't fight hard enough (or sic her grandchildren on her).

The waiting game began. It took three weeks to get a permission slip from the HMO to contact the neurologist my mother's doctor had referred us to. (Appointments cannot be made until the permission slip is in hand.) The neurologist

referred my mother for an MRI. More paperwork and more waiting. Claustrophobic, she dreaded the MRI, but she got through it. We waited another two weeks for a follow-up appointment. The good news: it wasn't Parkinson's. But now my mother would have to be referred for more tests.

**F**or months, we cycled from appointment, to test, to appointment, to test—all with weeks wasted in between. The HMO would approve only one very specific scan at a time, an example of the penny-wise, pound-foolish mentality

*A few months after her belated diagnosis, she asked that I write about her experience in the hopes that 'it could help someone else.' She was referring to her battles with the health-care system.*

of the HMO system. The doctor needed an MRI of her brain and spine. The HMO required three separate MRI's, starting with the brain. No disease there; scan the upper spine. No disease there; scan the lower spine. *Three separate sets of tests, waits, and follow-ups!* Not to mention that a terrified, claustrophobic, 85-year old woman had to go into that narrow tube three times. And still no determination as to what was causing my mother's loss of balance.

**(Tip: Weigh your decision about health coverage very carefully. Understand that you can always go to an expert for a second opinion as long as you have the funds to pay out of pocket.)**

Mother was eventually referred to a neurosurgeon—more tests and waiting. Offhandedly, last May, she asked him about the tiny little bump on her head, which he said was just a cyst. She asked several doc-

tors about it over the next few months; all of them seemed unconcerned—they were focused on her instability. By October, the "cyst" was the size of a small rock. Her primary physician decided to biopsy it himself, instead of referring her to a skin specialist. The lab results and a second opinion took another two months. Final diagnosis: melanoma.

In January of this year, her treatment started to pick up speed, because she was referred to an oncologist outside the plan. (Who knew that was possible?) The oncologist took one look at the now huge growth



*With the Lennon Sisters at a book signing at Henshey's department store.*

on her head and immediately gave her an urgent referral to a surgeon. (In all this time, we had never heard of an "urgent" referral.) The surgeon saw her immediately, and within three days he had excised the tumor. He did a great job, but the melanoma had already spread to her lymph nodes. The specialists were fast, but melanoma is faster. For us, there is nothing more to do now, no treatment options to pursue.

We will enjoy what little time we have—and smile. Here you are, Mother. This article is my last present to you. I love you. Let's have a party! □

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