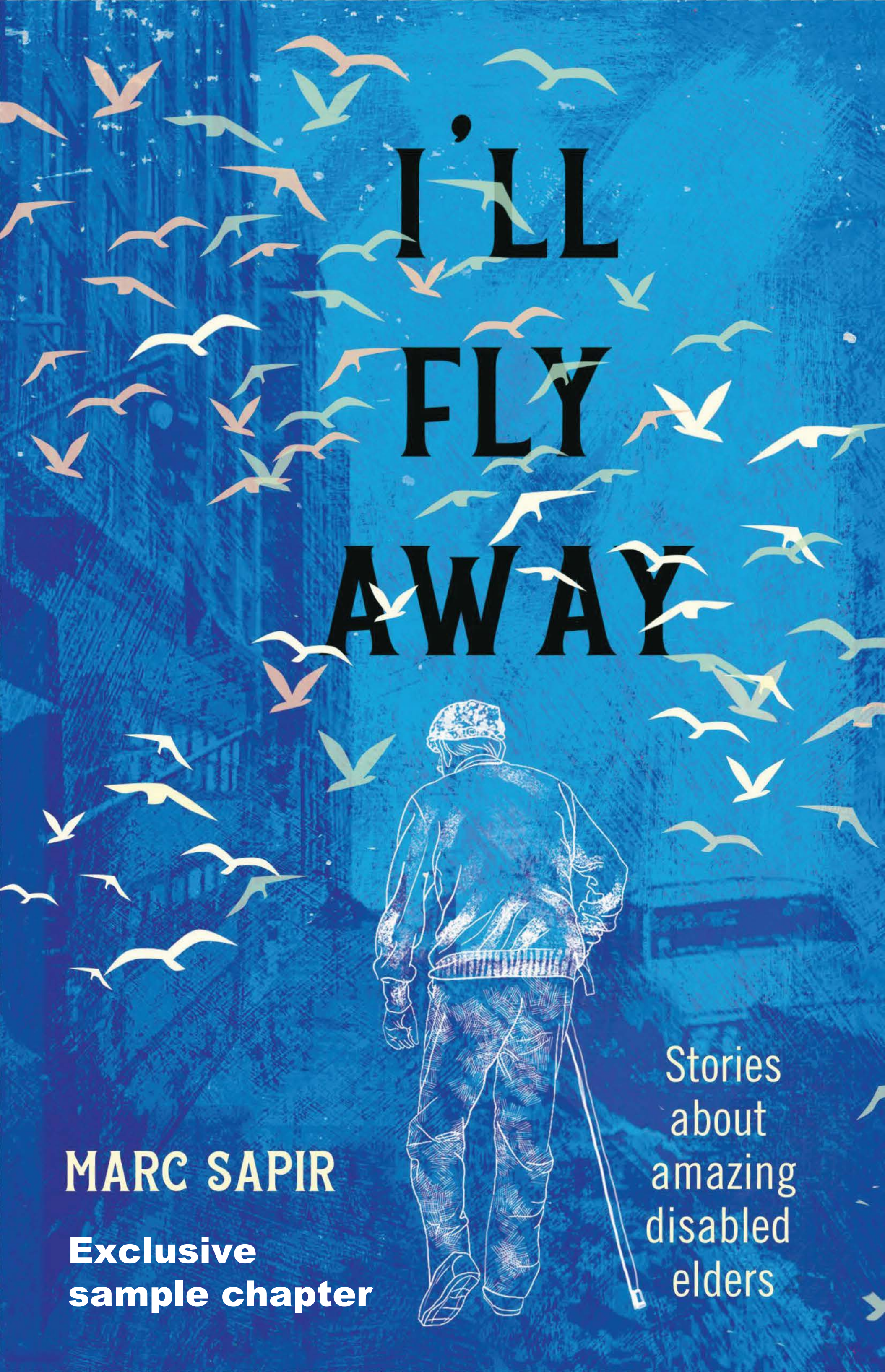

I'LL FLY AWAY

Stories
about
amazing
disabled
elders

MARC SAPIR

**Exclusive
sample chapter**

"I'll Fly Away," a 1929 song, is about freedom; it's also the title of Marc Sapir's beautiful book about 40 people approaching the end of life. Using the wisdom gained from the patient-doctor relationship and a Janus-like understanding of crossroads, we learn how looking back informs the road moving toward death. This alone makes the reader's time rewarding.

But this book is also an important reflection on how society supports (or does not) elders through their journey. Sapir elegantly argues that the fundamental values of cultural identity and community and their relationship with mortality signal our commitment to human dignity across life's continuum.

—*John Swartzberg, MD, FACP, University of California Berkeley's School of Public Health. Chair, Editorial Board, UC Berkeley Wellness Letter*

Initiation: The Rites of Spring

Ara Belle Kingsby[1]

In the early afternoon of Easter Sunday, April 1994, a deeply religious and dearly loved eighty-seven-year-old African American woman I knew and cared for died of pneumonia and dehydration. Beyond her children and grandchildren, the silky-voiced poet Ara Belle Kingsby left thirty-five great grandchildren and five great-great grandchildren to celebrate her "homegoing."

Editing down the epitaph written by her family:

Born Ara Belle Dalphinia George, the eldest of five children, in Mornings Port, Louisiana, Mother Belle as she was to be later called, graduated a valedictorian from the first high school for African Americans in Shrevesport, Louisiana. She devoted her life to family and community, married

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[1] It is customary, in presenting medical cases, to conceal the names of patients to protect their privacy rights. This essay was submitted to Mother Kingsby's family for approval because I felt that her particular historical individuality was a part of this story. As I suspected they would, the family photocopied the essay and distributed it to all of her children, who approved its contents and agreed that names not be changed. That was in July 1995.

twice, and had herself five wonderful children. She served as an elementary grade teacher, a local church and community missionary, a community activist, and a health nutritionist. In the 1940s, she moved to Oakland, California. In later years, she dedicated herself to her church and community work.

I first met Ara Belle Kingsby when I became the medical director and first physician at the Center for Elders' Independence (CEI), Oakland, Ca, in April 1992. She had a quiet, wispy, ethereal voice and a gentleness and a peacefulness about her demeanor. Despite that I was her physician, I did not take particular note of her, nor her past life, until a center picnic outing to Crab Cove, late the same year. Crab Cove is an idyllic small park on the San Francisco Bay, with green grass, groves of trees, and picnic tables set back from a sandy semicircular beach facing southwest on the Bay's eastern island city, Alameda. I had brought my old Gibson guitar at the request of our young white South African-born activities director and was just preparing to sing and lead the elders in a few songs including Negro Spirituals and folk songs. I began with Huddie Ledbetter's "Goodnight Irene."

Lead Belly, as he was known, became world-renowned for his songs—practically the grandfather of American folk music—after he was discovered in a Texas prison serving time for murder in a barroom fight by Alan Lomax and Pete Seeger. Due in part to their intervention he was released and joined the growing number of traveling folk singers in the 1930s and '40s.

Climbing up on a picnic table so I could be seen by all the elders, I introduced the song by asking how many had heard of Lead Belly. Most of the thirty-five or so folks there raised a hand or cried out in affirmation. Then I heard that wispy voice of Ara Belle from the farthest-out table call out, "I knew Ledbetter."

Despite her ethereal voice, Ara Belle Kingsby was a strongly framed and far-from-frail-appearing woman. She was hefty, though I wouldn't call her obese—still attractive in her mid-eighties. She had a lilting Southern accent. "Tell us about that," I asked of her, and she continued: "His sister married my brother. After he got out of prison he would come by our house in Shreveport and talk and sit out on the front porch and play guitar and sing of an evening. All the people from around would come over when he started to sing and play. I remember him real well." Living history from over fifty years before blossomed before our eyes and ears, totally unexpected.

Listening to the stories of other patients' lives, I realized that these folks in our Program of All-Inclusive Care for the Elderly (PACE model[2])—most of whom, though living in Oakland, were Blacks

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[2] A rudimentary description of the PACE model may serve the reader of these essays. Seventy to eighty PACE programs across the country effect a very specific model of care for frail and disabled elders. To gain entrance elders must be certified as disabled and at risk of nursing home placement, then join the program and get all their medical care from that program although they live wherever they choose out in the community—often with family and support in the home. Program goals include keeping people out of nursing homes and other institutions through the end of life and maximizing quality of life. Although PACE may use hospice methods sometimes, PACE differs from hospice care because many participants are not terminally ill, and some members have survived ten to fifteen years in the program. Each PACE site has several adult day health centers with daily programs providing social activities, a medical clinic with doctors and nurse practitioners, and physical therapy. The care and care planning of members (participants) is coordinated through broad interdisciplinary teams. Teams of a dozen or more professionals and semi-professional staff (including drivers, social workers, therapists, day center staff, and medical staff) meet daily to discuss care plans and problems—chronic or new—of participants in that program—including non-medical, social, family, housing, and other problems as well as medical issues. Participants may be seen in the clinic or the therapy center daily (as needed), and care plans can be changed according to changing conditions, at any time. The social activities of the day center are central to the program. Other details are suffused within these essays and more info about PACE can be found at www.npaonline.org.

raised in the South—held within themselves a treasure of living history. And so, I decided to organize a reading and reminiscences group for mentally high-functioning members. The group, which I'll return to later, met in the day center almost weekly for many years.

But at Crab Cove, hearing Ara Belle's brief talk had taken me by surprise. I had sung and listened to Lead Belly's songs then for over thirty-five years. "Goodnight Irene," a sorrowful prison lament, had a particular significance to me because I had been married to a young woman named Irene. We divorced after only two and a half years of marriage and I later learned from her mother that Irene had died of liver cancer at the age of fifty. In any case, this introduction to Ara Belle Kingsby as relation to Lead Belly began for me a new and different type of relationship between us, and for me a greater insight into how fortunate I was to be so engaged with this community of elders at CEI.

PACE program members live out their lives in their own homes. All entering participants to any PACE program are asked how they want to be treated or not treated in crises and potentially end-of-life situations. Ara Belle Kingsby, from the time she entered the program, stated that she did not want to be hospitalized or placed on machine ventilation in the event that her heart stopped. She based this on religious convictions. She had lived, she said, a long, satisfying, and prosperous life—had a large extended family. She was prepared to pass on when called by her God. She believed she would be going home to a better world. Doctors were only going to add unnecessary burdens.

A few short months after I arrived at CEI, Ara Belle had an abnormal PAP smear (a test no longer recommended for women this old). She acceded to a biopsy by a gynecologist, and this showed moderate cervical dysplasia—possible early signs of cancer. As a result, our nurse practitioner then scheduled her for a recommended, more extensive curative biopsy procedure called a LEEP. On October 14, 1992, a day before the procedure, Mrs. Kingsby declared that she would not go. She spoke carefully and calmly, without any touch of hostility in asserting that it would be best if she were left alone. About this same time, she also refused to go for a recommended eye exam to check for glaucoma. She clearly said she did not want to be bothered with all of these doctors. I had been medical director of CEI then for only five months.

Just two months later, Ara Belle developed a rapid irregular heart rhythm and was briefly admitted to the hospital. A short time later, in January of 1993, she developed a blood clot in a leg vein and again required a brief admission to start on anticoagulation. In the tension of these episodes of acute illness, she did not resist the care strenuously but when her general condition was more stable, she again asserted during her regular complete exam (this time to a woman physician on our staff) that she wanted no treatment for her cervical dysplasia.

Nevertheless, on June 30, at her next quarterly examination, at my persistent urging, she acceded to see the gynecologist anyway. Ominously, I also noted she had an enlarged liver and an easily felt abdominal mass as well. A C/T scan was done with her agreement and revealed two different masses in her colon, one probably expanding into the gallbladder.

Meanwhile, Ara Belle had been again scheduled for the cervix (LEEP) procedure. A tug of war was going on, and in retrospect, Ara Belle was wiser than we—our medical staff—given that her abdominal mass was menacing her, not her cervical dysplasia. On August 9, after being taken to the gynecologist's office by our transportation staff, Ara Belle emphatically refused to transfer onto the table and then insisted that no further evaluation be done.

Once back at our day center's clinic, she again patiently told me that her life was in God's hands and she would like me to let her live and die as God wished it. She did not raise her voice and showed no anger. I then realized that I (and others as well) had been refusing to listen to her wishes. I had simply not wanted to "just let her die." Somehow it had seemed to me too early in her medical evaluation—despite her age. In consultation with Ara Belle and her daughter Ruth, however, I agreed to better carry out her wishes. A gastrointestinal procedure to diagnose the abdominal masses was canceled. Ara Belle well understood all the time that she might have an abdominal cancer and that she was risking its spread without treatment.

At the same time, though understanding that I should carry out her wishes, I was becoming frustrated, still failing to see that I had to give up the typical medical role for Ara Belle. I felt that, as a doctor, I now had very little to offer her. And, moreover, that the clash between our two value systems and personal judgments about her situation lent itself to personal failure for me. I liked this proud woman, but unlike some of the feisty, sometimes obnoxious, people I had to deal with, who I could easily laugh with, she was unnerving me. In her priestly, gentle way, Ara Belle had an untiring resolve; she was unbelievably forceful in her gentility. She challenged my self-defined role as physician. The situation was complicated, and I was new to geriatrics, to dying and palliative care.

I have had patients to whom I could minister mostly emotional support, companionship, guidance, and a soothing influence, even when I had little to offer as a curing physician. I have always recognized that the doctor's role is as much caring as curing. *But what if Ara Belle had a curable cancer?* I thought to myself. *And besides that, what could I offer someone so accepting of death in her righteousness?* Thus, when a second doctor joined our team and I had to divide the patients between us, Ara Belle was one of those who I passed on to him, with her permission. She expressed no concern. We saw and spoke to each other frequently and she greeted me cheerily each time, nonetheless.

Ara Belle's situation did not deteriorate for some months. Then, in September 1993, Ara Belle Kingsby suffered another deep vein clot in her leg and was hospitalized for five days. Two weeks later, at a family conference with her new doctor, her daughter, and her social worker, she again made herself clear, declaring that she wanted "no further work-ups" of her medical problems. Three weeks later, she came to the center with visible blood in her stool.

By December 21, she had developed right-sided abdominal pain in the area of the mass; she did not want any evaluation. She was treated with pain medications and her condition again stabilized for a while; but on March 7 1994, she was hospitalized for two days with a kidney infection. A day after leaving the hospital, she came into the center seeking to be seen in clinic. I examined her for complaints of vaginal and anal pain, and found she had become incontinent of both urine and stool. Her stool was brick red and tested heavy for blood. Her blood level had fallen progressively over a one-month period; she was anemic, anxious, and in pain, and under these circumstances she agreed to my insistence that we order colonoscopy to finally identify what was happening and whether we doctors could do anything to help. I wanted this done, though now believing her cancer incurable, because it might be possible to prevent a bowel obstruction—a terribly painful way to die—or to stop the internal bleeding. That would be a useful palliative measure to make her end less difficult. Meanwhile, we treated her abdominal pain.

At colonoscopy, the gastroenterologist found that the higher-up mass was, as expected, bleeding and an invasive cancer. It was too advanced to be removed via colonoscopy. With these findings, Ara

Belle's answer, firm as it had been so many times before, now communicated through Ruth, was "she doesn't want any surgery," not even to prevent an obstruction of the bowel. The following week, Ara Belle came in to CEI in even worse pain and she was jaundiced. Under these stresses, she did accede temporarily to seeing the surgeon. Two days later, before evaluation by the surgeon happened, her jaundice was worse; she was bright yellow, and the mass was very tender. Our usual surgeon was in surgery all day, so I scheduled her to see him the next morning, but that wasn't to be.

At 5 a.m. that morning, I was awakened by a phone call from Ruth that Ara Belle was unable to breathe, and Ruth had called 911. I met them, and many other family members, at the hospital emergency room. Ara Belle's blood pressure had fallen to 60/40, with a pulse of 130 and her hemoglobin six and falling, reflecting potentially life-threatening blood loss; but she was conscious, alert, breathing well, and as usual, calm and reflective.

We had talked about palliative care. I had discussed with Ruth the issue of Ara Belle dying at home in her own environment. But now they both preferred that if she were dying, she spend her last days or hours in the hospital with nursing attention and family by her side, and so she was admitted.

At that moment—knowing that Ara Belle Kingsby would die from this malignant condition (later if not tonight)—I found myself finally ready to think and act as if I were Ara Belle Kingsby herself rather than as her doctor. We worked on the palliative principle that Ara Belle, who reiterated again very clearly and even blissfully that she was now ready to leave, was in the hospital only to make her dying easier, with less pain and suffering.

Although this palliative approach is followed every day by practitioners in hospices and hospital settings for terminal cancer patients, my relationship with Ara Belle had unfolded in a most unusual way. As I have mentioned, when I was appointed medical director of CEI I had already been practicing family medicine for twenty years, but I had little geriatric experience and no end-of-life care expertise. I was now the student of Ara Belle as well as her guide.

Ara Belle was admitted to the oncology ward for cancer patients who were under palliative care. The first day I did nothing but prescribe small morphine injections for pain; her condition did not change; she was alert; she ate dinner, shared time with dozens of family and friends, spoke about her passing as a blessing. At night, she began to have more pain. With the advice of staff nurses, her treatment passed on to an intravenous morphine drip which would, I hoped, control her pain, but also the desire to eat or drink; Ara Belle became more lethargic, but also pain-free. But on the third day she showed no signs of weakening. Her body was strong. We did not give transfusions for her severe anemia. Then I realized that the IV, which had been placed only to allow access for medications, was providing her some sustenance. The IV fluid rate was decreased to almost nothing, though she was provided any oral liquids she desired.

At the hospital, I visited with her daughters and other family daily and I told them she would likely die within two or three days from dehydration, a painless, almost dream-like death. But Ara Belle was not yet ready to die. In making such a prediction, I learned an important lesson about the unpredictability of the trajectory of life and death even under such conditions. Ara Belle wandered in and out of consciousness and mental clarity and did not die.

As the days went by, I now recall, I had some misgivings about my decision to not do anything besides pain medication. I doubted myself, worried that somehow, I had failed her. The family, on the other hand, remained close by and calm. Each daughter and her son fondly provided me, as well as Ara Belle, their support; told me I was such a wonderful person to be there daily going through this with them. I re-examined my ambivalence, accepting that, even if we "brought her back to life," Ara Belle would only suffer a more tortured death from metastatic cancer—soon, very soon; or worse. To force her in this, the gravest moment of her life's vulnerability and hypersensitivity, to noxious stimuli, to have the palliative (not curative) surgery she never would have wanted, to suffer that pain and indignity as she was dying, would have been a terrible decision.

As firmly as the family stood by Ara Belle, they stood by me standing by Ara Belle. That helped me develop confidence in my shamanic-like role, which was as much a symbol of caring as it was anything else. As her state worsened, we progressively raised the level of the morphine drip to treat her restlessness and any apparent pain. She became semi-comatose and more relaxed. The hospital nurses on this ward had been through this dying process with cancer patients hundreds of times before and they offered suggestions and parameters for the morphine drip. I was using morphine levels that were common for terminal cancer pain, they assured me; we were not doing anything unusual under the circumstances.

Two nights before Easter, Ara Belle had an increase in muscular spasms and tension. With my doctor mind I could imagine: uremia from her kidneys shutting down; electrolyte abnormalities; hypocalcemia, hypercalcemia, or other causes of nerve-muscle membrane instability; hypoxia and acidosis, the pneumonia she had now acquired. *I could guess but not know; I must not become the "distant" investigator,* I thought. Clinical diagnosis and treatment was not my role. I ordered the morphine to be upped to the "usual" maximum dose and I imagined inside Ara Belle's mind: Ara Belle wondering if she might have the privilege of dying, of being resurrected—for she surely believed she was going home on Easter Sunday.

On Easter Sunday morning, I visited Ara Belle and three of her daughters, and found her comatose and relaxed. The neuromuscular instability had been broken by the morphine. Her breathing had now become agonal. She was dying. I suctioned her briefly myself, talked with three of her daughters—Georgia, Ann, and Pam—and stayed around a while believing she would die then. It was now the tenth day since her admission. But I had also given up thinking that I could predict the procession of this process. The family was calm and resigned to her death. I went on home. Ninety minutes later, around noon on Easter Sunday 1994, the nurse called to tell me that Ara Belle Kingsby had died.

Two days later, four of Ara Belle's five children attended a prayer circle for her at CEI and presented me with a scrapbook of photos of dozens of family members taken during the prior ten days in and around Ara Belle's hospital room. Seeing them taking flash photos, I had—on the second day—asked if I might have some family pictures. And despite their family crisis, they had gone a step beyond and assembled this scrapbook. At the prayer circle, they spoke of poems that Ara Belle had composed for each of them when they were children, and they read some of her religious poetry.

I also spoke—though not of Ara Belle's enduring faith—but of the wonderful support that she and her family had given me as we had moved through her dying process together. "I cannot imagine," I said, "a family (including my own) giving me better or more deeply felt support than I have received from this family. It is an honor to have served and known them."

From Ara Belle Kingsby, I learned more about myself than I would have thought could happen. Because I am Jewish, I have never believed in euthanasia. I identify assisting death with eugenics; with the reality that governments do try to decide who is to live and who to die, who is too old, too frail, too dangerous, inferior, and expendable. I am also uncomfortable with the idea of someone assisting the death or suicide of a person with whom they are not deeply familiar, because what a person says they believe or want at any particular crisis moment may or may not reflect the totality of their lives, their values, their being, themselves. But I learned from Ara Belle Kingsby and her family that, if only we try, people can allow each other to get close enough to understand and do the right thing.

What I also learned from Ara Belle is that some of the gifts of life can come to us in the most unimaginable ways and from the most unexpected others, such as in the form of death and dying friends and patients who simply reach out and ask to be understood and accepted, still, as equals.

First draft written 1994.

How Death Saved Barbara's Life

Barbara was looking for a real home. She came to us almost lacking an identity, almost a non-person. She did have an apartment, unkempt, reflective of her disorganized, withdrawn, and depressed self. It was in an unsafe neighborhood in Oakland. It was all she had; that and a distant, dismal past, and no sense of a future. Her married name sounded Italian; but her own background never came into focus.

Barbara had been long estranged from her two living daughters (children by different alcoholic husbands). One daughter refused to ever visit or talk with her. Barbara herself had a lifelong history as an alcoholic and as a mother who had neglected her children and had had them taken from her. She carried a diagnosis of chronic schizophrenia and was being maintained in the community by the County Mental Health clinic on a dose of Haldol (twenty-five milligrams) that would probably put you or me to sleep for days. Despite the diagnosis she carried, however, Barbara had for many years manifested only social isolation and withdrawal with no psychotic behaviors, hallucinations, or delusions. But she did almost nothing, except chain smoke. And she was just a sad sack.

Five-foot three inches, with an indifferent look, coarse reddish-brown-graying hair, an average build, a wardrobe neither striking nor particularly shabby, and a weight of 122 pounds, Barbara didn't stand out in a crowd, except for a tendency to protrude her lower jaw in an underbite, and her anxious pacing which suggested a restlessness living just beneath her stoical surface (perhaps a side-effect of her medications).

Everything about Barbara suggested an inner world of resignation. She rarely initiated conversations with anyone. Her moderately lined face, though not unpleasant, had the appearance of a hardened mask. She sometimes seemed to float above the ground like a specter; at other times she paced like a zombie. She responded only when probed, though she was intelligent and observant. Her memory and her thoughts were often clear, even sharp and perceptive, yet fleeting; and she seemed so indifferent. Like many elders with schizophrenia, the disease—and perhaps the years of medication—seemed to have burned out her life force.

When Barbara was referred to the Center for Elders' Independence (CEI) she was, at sixty-seven, nine years younger than the average participant. She had been recently hospitalized for shortness of breath, the cause of which was not determined. No pelvic exam had been performed, but she was referred to a community gynecologist for a vaginal exam due to an odor. The gynecologist had found that she probably had a cancer, and many symptoms that she had been ignoring and not telling anyone about. This doctor was unable to perform the exam adequately for a diagnosis.

The day of her initial visit to CEI, I consulted a different gynecologist and then referred Barbara to a radiation implant specialist for full diagnosis and treatment recommendations. Not only did we hope to help Barbara get rapid treatment, but our multidisciplinary team needed to know if she was likely to survive long enough to benefit from our day center and comprehensive support program; we needed to decide if she was a candidate for team evaluation and admission.

The specialist's answer came back in a matter of days: it was an invading cervical cancer that had expanded into the bladder and out to the walls of the pelvis, forming a tract between bladder and vagina that drained urine. But the tumor had not yet spread to lymph nodes or distant organs. Once radiation treatment had shrunk down the size of the tumor there might be a small possibility of cure of the cancer. She would also need to have tubes put in her kidneys through her back to drain her urine because either the tumor or the radiation would probably block the ureters. And since she was also having a lot of local infection and irritation, these could get more serious if we allowed urine and debris to drain constantly.

But Dr. Demanes thought that even without cure Barbara could maintain a stable quality of life for a year or so with treatment. He offered to stay closely involved in her care for the duration, not just during her treatment phase. As Barbara then agreed to be treated, we decided that she could benefit from CEI and enrolled her.

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Stoic and depressed as she was, Barbara went through the heavy radiation treatments as though it were like getting dressed and brushing her teeth in the morning. She had her kidney tubes placed; they blocked or fell out periodically and she would have to return to the hospital to have them replaced. The radiation procedures involved repeatedly placing a large insert with many radiation probes inside the vagina and pushing it high into the pelvis. There must have been pain, but she never complained or admitted to much. “It was kind of uncomfortable,” Barbara said. And then, “It did hurt a little when it was in there,” she would casually monotone. We had sent her to live in a nursing home for supportive care during, between, and after treatment as a temporary measure. Barbara lived at that convalescent hospital for three and a half months.

Meanwhile, she became a regular attendee at the day care center, finding places to lie down, rest, or sleep frequently, but nevertheless getting to know staff and participants and slowly making a new home. She still had the attention span of a hyperactive child. She would come into an activity, sit for three to five minutes, then get up and wander restlessly about the center or find somewhere to lie down; or rush outdoors to chain smoke compulsively.

So, our team tried to develop an interactive strategy to engage her, calm her, and slow down her restlessness. This included bingo on Wednesdays, small tasks, a try at the Reading and Reminiscences group, symptom management with her social worker, Rachel, drama therapy on Thursdays, art and mural work and talking with Rachel on Mondays, working with children when they visited, and so on. I steadily reduced her Haldol dose and decided to treat her depression if it didn’t respond to the social stimulation. We waited to see if she would become more agitated on less Haldol.

Often now I came upon Barbara sitting in the hall, smiled at her, took her hand, and talked with her briefly. As time passed, staff members, especially Rachel, were also developing a more interactive relationship with her. But Barbara's responsiveness was marginal. She seemed disinterested in life's nuances. Still, she offered that she liked the center, and felt supported.

When she started at CEI, Barbara was told, and she acknowledged, that she had a serious cervical cancer that had spread, but amidst the talk of treatment, and "possible" cure, and the support she received—as she later expressed herself—"I thought I was getting better." In a sense, she was right. On the other hand, denial ran—had been running—rampant through Barbara's conscious life for a very long time before this. It wasn't just death or the cancer. I hoped that, if perhaps briefly, denial might serve her positively. Besides that, one kind August day with treatment completed, the team returned Barbara to the community to live in a small residential home.

Improved independence, improved health. Barbara heard her doctors say that the tumor was shrinking. And in the first six months or so her weight had returned from 100 back to 120 pounds and her strength improved even during radiation treatment.

Despite new stable surroundings, however, Barbara soon became progressively weaker, with recurrent weight loss, and increasingly difficult ambulation. She began to faint frequently after compulsively smoking cigarettes, finishing each one in about thirty seconds; she fell and had several minor injuries, once requiring five or six stitches to her scalp. She was obviously anxious and worried. Asked if she thought her cancer was getting worse or the fear of that possibility was bothering her, she flatly denied it. I started her on an antidepressant.

The CEI team noticed the changes and intensified the effort to involve Barbara with a painting project, for she had wanted to paint again. She got partway through, putting in five to ten minutes each day at the center during two different weeks; she sat in a Reading and Reminiscences group for only a few minutes. Though she anxiously sought cigarettes and, if not provided, smoked butts she scrounged or scavenged in the street and ashtrays, on some intangible level she seemed to be feeling more secure. I wondered how, paradoxically, Barbara could be feeling better and worse at the same time; I could not understand this contradiction then.

Throughout those months, Rachel and I maintained close contact with the daughter who had become, the past year, very involved in her mother's support. Sheila, fortyish, a woman who seemed to share Barbara's serious and unreadable facial expression, worked successfully in a professional capacity with a local county health department. She had helped Barbara to accept us and the various housing changes we pressed on her. Barbara had initially resisted leaving her own apartment; and though Barbara had successfully moved in August, a while after returning to the community she initiated—through slovenly fecal incontinence—a confrontation with the residential homeowner and was expelled. But now, by early 1994, despite the fainting, the weight loss, and weakness, things had calmed on the home front. She was happy with her second new home of three months—as she was with CEI—and these were important areas of calmness and achievement.

In early February, at her new Board and Care home (the Nest), which she shared with four or five other residents, Barbara became increasingly withdrawn; she started to stay in bed all the time at home and to resist coming to the day center; she began to have more frequent stool incontinence. Her Haldol was increased from five to ten milligrams. Now she became dramatically weaker, confused, and increasingly more withdrawn.

This apparently was not a psychiatric flare-up. Blood tests showed that Barbara had hypercalcemia (known as the para-neoplastic syndrome—due to regrowth and spread of her cancer) and had become dehydrated, explaining her increased weakness, confusion, and withdrawn behavior. She was hospitalized, treated with intravenous fluids and Pamidronate to lower her calcium, and this rapidly—though only temporarily—rejuvenated her. Just two days after admission, she was lucid and alert; and so, with Barbara's agreement, I called Sheila and asked her to come to the hospital for a much-needed conference.

Barbara was able to walk from her room to a big, well-decorated lounge at the end of the corridor with comfy sofas and chairs spread about. She came without support, wheeling her own IV stand. She sat down; she sat quietly, peacefully smiling at times. "I'm sorry to tell you that you are dying of the cancer," I said. Whether weeks or months remained to her life, I could not know, but the process was inevitable, and the calcium problem would probably keep returning until then. "Did you know that this was coming?" I asked Barbara.

"No, not really," she responded. "It seemed I was getting better."

Then Barbara and Sheila calmly and warmly shared their feelings and fears with each other for an hour on that Saturday morning in the empty hospital ward lounge that was way too big for three people seated alone in a tight group. I sat witness to a sadness and a harmony blended into a common acknowledgment of each other and of themselves. For Sheila, particularly, it was an epiphany, because she and her mother had never, to her recollection, shared so much.

But what did Barbara feel; Barbara, who was dying? Finally, I asked her if she was frightened, for she had often said that she was afraid of dying and wanted to live. "I'm not afraid anymore," she replied directly. I heard a lightness and relief in her voice. Did I imagine this? Was I projecting? Well, no.

Barbara stayed in the hospital a few more days and then went home to her Nest. We agreed upon a plan of support and palliation. Her center days were cut back to three a week and I told her she could be in control of whether or not she came in and whether to continue her medicines. On any particular day, she could stay home if she wanted to.

Immediately, she showed a new outward assertiveness. At the center she began openly discussing her impending death with people she related well to. She no longer was interested in smoking. She did decide to stay home more often, but she was not withdrawing. On March 17, with her wanting to stay home more, I negotiated two days a week at the center with her, telling her I needed two days to monitor her medical state. She agreed.

Later in the day, back home, she refused all medications, including her Haldol. By phone, I could not convince her to reverse the decision. My goal had always been to get her off psychiatric drugs and she knew it. Barbara was not hostile; to the contrary, she was friendly, peaceful, and determined. Now she spoke more frequently, and still more forcefully and assertively. She smiled more spontaneously. She was relaxed and she initiated topics and conversations. At one point, out of character and somewhat out of context, she said to me, "Dr. Sapir, I just want to tell you how thankful I am for your kindness."

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On March 18, now two weeks after Barbara's hospital discharge, the staff at the Nest went into rebellion over their fears of someone dying at the home. They had been instructed that Barbara was terminal and that both she and CEI hoped to keep her calm and happy until death at home (residential care staffs are not licensed nurses). Placing Barbara, who was not demented, in a nursing home at this time would be taking away her home and security for no reason. She was finally achieving some sense of self, some real autonomy, and with this an ability to direct her own life positively, with dignity.

Our program's home nursing director visited the Nest home staff and gave them an in-service on terminal care and dying patients and assured them that we would manage any medical issues twenty-four hours a day. She helped the staff express their personal fears. Though no permanent agreement was reached, peace was restored. At least for the moment, Barbara could stay, and the team assigned a health worker to spend several hours a day supporting her at home to supplement the staff of the Nest.

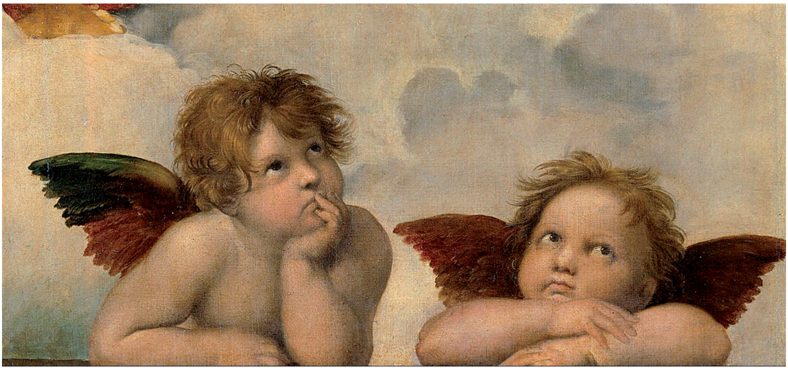
Now, over the next week, Barbara's hypercalcemia began to return, and she became weaker and unable to come to the center. She stayed in bed much of the time. Nevertheless, she responded to encouragement and continued to keep up her intake of liquid and calories by mouth so that she did not suffer the disorientation that had caused her earlier hospitalization. In the midst of an overwhelming cancer burden, she remained in focus, in harmony, and intact. And she was not becoming depressed. She received intensive support from Denise, her Home Health worker who had strongly bonded with her.

On March 23, with Barbara no longer able to attend the center, I also began home visits. The next day, she was calm and resting. I sat beside her. We conversed about her contentment with the room and bed location that she had. From her room, sometimes even from her bed, she could watch the squirrels in the back yard playing in the trees. "I love to watch the squirrels," she said, smiling. "I'm not afraid of dying," she told me, now at her own initiation. "And I'm ready to die."

Four days later, Barbara did die, peacefully, in bed at home. That very same day, she had still been able to get up with a little assistance and walk to the bathroom. Her incontinence had improved dramatically and there was no indication that her life was at its ending. A few minutes before death, she had actually been up talking. I thought: *Barbara's death had become one of the most vital and developed works of her difficult life; it was a work of art as well as of her humanity. For her death was serene. Or it at least appeared so. What evidence?*

Time passed after Barbara's passing, after her wishes to be cremated had been carried out, after a remembrance and prayer ceremony had been held with the participants at CEI's day center. One day, Sheila stopped in briefly. Thanking me for helping her regain a meaningful relationship with her mother, Sheila agreed that Barbara had found both inner peace and some kind of meaning in the last weeks of her life.

Then she handed me a sealed envelope that Barbara had asked her to deliver to me. The envelope was simply addressed, "Dr. Sapir." I had no idea what to expect. I hesitated briefly, then opened it. Inside was a card. On its front, two cherubim gazed upward toward heaven from a famous Raphael painting, faces posed in idyllic wonderment. I opened the card. Inside was written "Dr. Marc Sapir," then the imprinted words, "Seasons Greetings." It was signed simply "Barbara." Though briefly stunned, I began to chuckle and could almost feel Barbara's presence. This card hung on my bulletin board beside my desk at CEI for years. As I looked up or still think of it, I could never, can never, help from smiling, warmed by the black and wry humor of Barbara's post hoc greeting—and remembering the harmonies of her passing. My glimpse of Barbara's humanity, poignantly revealed—as well as the wonders of PACE—evoked this essay.



Barbara F.'s after-death greeting card (from Raphael's Sistine Chapel painting).

Retired family, community, public health doc and activist, Marc Sapir, writes plays, essays, fiction. His satiric novel about the second Bush war on Iraq (*The Last Tale of Mendel Abbe—Sonny Bush and the Wise Men of New Chelm*) was self-published (2004). Marc lives in Berkeley with wife and rotating grandchildren. His memoir, *Deja Vu with Quixotic Delusions of Grandeur* was published in May 2024 and is available at Bookshop, Amazon or through your local bookstore.

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Could the lives of 40 disabled oldsters in a geriatric program make interesting reading? “Interesting” is an understatement. These stories are fascinating. From end-of-life tales, demented women engaged in sex, a man on oxygen lighting himself up with a cigarette, a Mexican American family trying to remove their mother from control by their schizophrenic brother, a 99-year-old couple attempting to drive across the Arizona desert in midsummer without air-conditioning, each person’s tale is unique, carefully told by Dr. Marc Sapir who unfolds the complexity and humanity of the program’s charges.

Anthony Somkin MD,
medical director RotaCare West Contra Costa

These stories ring true and reflect a deep commitment to progressive team-based community health and the people who community clinics serve. Dr. Sapir discusses complex and difficult decisions that must be made and the challenging social contexts with kindness and insight.

Khati Hendry MD, former medical director Clinica de la Raza,
Oakland, CA and the East Bay Community Health Center Network

A collection of wonderful real-life stories on aging. Marc vividly portrays a complex series of human emotions, struggles, conflict, interactions, and relationships. “Families and Kin Folks” is a case study of family superinvolvement in one of their own’s healthcare decisions [with] a colorful picture of the family dynamics, social and cultural backgrounds that all play a part in these kinds of conflict…[Marc’s] description of Ron, the last character in the book who was a CEI staff member well represents the book. “That jumble of contradictions that was Ron, is just what it is, what we humans are about.”

Thomas Irungu MD, MPH, medical director Sentara Health Plans, VA

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