

SAVING SANDY: A STRUGGLE WITH A RARE BRAIN CANCER

James H. Williams, Ph.D., Savannah State University

A spouse develops a rare terminal cancer. She and her social worker husband struggle to find treatments and, eventually to face death. A social worker revises his practice perspective.



In the summer of 1995, my wife Sondra "Sandy" Patrinos began to experience strange symptoms. She would become disoriented and had difficulty seeing and keeping her balance. A visit to her primary care physician began a series of encounters with a complex medical system. She was referred to a neurologist, who began a battery of tests. A CAT scan revealed a lesion in her brain. More tests were ordered, each seeming progressively more intrusive. Our fear and frustration grew accordingly with each inconclusive test. We were in the clutches of managed care, which meant that each test had to be scheduled individually at different locations. This took time and we were running out of patience.

A brief biography: Sandy and I were from working class families. After a lifetime of political and union activism, we had gone back to school. Sandy was a fighter. One of two daughters born to a Jewish Communist family, she grew up in a tough neighborhood in Philadelphia. Her first political memory was helping her mother distribute literature for Henry Wallace's Progressive Party in 1948. At the age of 15 she joined the Communist Party- later becoming head of the CP in Eastern Pennsylvania. As the nation emerged from the McCarthy period, Sandy became the public face of the party in Philadelphia. Later, in Chicago, she was director of Women for Racial and Economic Equality (WREE). She was known for her tenacity and determination never flinching from a fight simply because the odds were stacked against her. (She finally left the Communist Party in 1990.)

This cancer was to get the same treatment from her. In 1993, we both graduated with professional degrees: I had gotten a Masters in Social Work (MSW) and Sandy a Masters in Public Administration (MPA). Sandy got a job at Cook County Hospital in Chicago, to develop and run a mobile mammography unit. I started working with mentally ill and substance-abusing persons in the criminal justice system. By 1995 we felt as though we had finally settled and we were both doing work that we found interesting, and we were making, for the first time in our lives, decent salaries. We even bought a nice co-op apartment.

As the tests dragged on, Sandy's symptoms began to impair her functioning more severely. The tests revealed what we had feared: Sandy had a brain tumor. To find out what kind of brain tumor, a stereo-tactic biopsy had to be performed. We had to wait a month for our managed-care approved provider to schedule the test at the University of Illinois hospital. As news of Sandy's predicament spread through Cook County Hospital (CCH), a top specialist at the hospital offered to do it there. We knew he was good since he had trained other doctors at the University of Illinois facility.

The day of the biopsy, Sandy was all prepped and ready to go. She had spent the night in a ward at Cook County Hospital, a hospital which was in dilapidated condition, but whose staff struggled valiantly to provide excellent care. As she was wheeled to the operating room, I walked alongside clutching her hand, trying not to show my nervousness.

Trying to be strong. We passed a priest in the hall. He made the sign of the cross over Sandy (a Jewish atheist) and blessed her. She smiled and thanked him.

When we parted at the operating room doors, I was left standing in the hall. Many of Sandy's friends from the hospital were able to get into the operating theater. That's when I felt really alone. The biopsy revealed brain cancer - primary central nervous system leukemia, (PCNSL) which is a very rare form of cancer. It is terminal and few patients had lived more than a couple of years.

Sandy had a wonderful, caring oncologist who impressed us on many counts, but we most appreciated her readiness to include both of us in decision-making and to enable a participatory process in treatment. She confessed that she had never encountered this extremely rare cancer before. She supported my frantic search for information and treatments: many doctors would have considered this unwarranted interference. I searched the internet (still somewhat in its infancy in those days). I began to call around to various hospitals and labs that specialized in cancer. People at the M.D. Anderson Cancer Center in Houston were helpful in assisting me to learn about the cancer, and they also recommended Memorial Sloan-Kettering Hospital (MSK) in New York, where Dr. Lisa DeAngelis (1999) had successfully treated patients with this disease. Dr. DeAngelis is a renowned expert in this cancer and she had developed a treatment protocol that showed promise. Dr. DeAngelis' treatment was a tough regime of full-head radiation and some possibly dangerous chemotherapy (Correa, et al., 2004). From what I learned, the treatments could result in some permanent cognitive damage. But without treatment, Sandy didn't have long to live. We hadn't expected a trade-off like this. What would it mean for Sandy? Reluctantly, we concluded that this was the only choice open to us.

Our oncologist continued to be open to working collaboratively with me. I was surprised at her willingness to put up with such a frantic, intrusive husband. We all three sat down and had a long discussion, weighing the

pros and cons of treatment. Sandy agreed that she would try the protocols developed at Memorial Sloan Kettering Hospital.

We began a long period of alternating treatments: first a series of whole-head radiation, then a series of chemotherapy. The chemo took place over a 24-hour period in the hospital and was injected directly into Sandy's brain. When the treatment was over, the doctor gave us a prescription for an antidote to the treatment's toxicity. Unfortunately, when I tried to fill the prescription, the drug was not in stock. I really panicked then. I was faced with a toxic chemo that could hurt Sandy, and I could not find the antidote! However, our oncologist came to our rescue and arranged a shipment of the medication to the hospital pharmacy.

After some weeks, it looked like Sandy had achieved remission. The tumor had receded. Her hair grew back; she fleshed out again and got her color back. Sandy decided to go back to work at the hospital. She could no longer drive, but it was easy for me to drop her off and pick her up. The mobile mammography project at Cook County Hospital, which she had founded, was designed to give poor women in distant areas in the county access to mammograms. The program was under funded and understaffed, and Sandy pushed herself to make sure that the project continually made the rounds of some of the poorest areas.

This remission was an important milestone for us. We were able to travel again and could visit her relatives. We went on a vacation to Spain. I had long promised a vacation to take her to Europe, and we went and spent a pleasant week in Madrid going to museums and visiting with striking Spanish workers, who had conveniently set up a tent city across from the Prado museum.

While most of our family and friends knew about Sandy's situation, Sandy had not told her 85-year-old father how sick she was. She was afraid that he would be adversely affected by the news. When we visited him in Philadelphia, she appeared normal and healthy. Her father never knew that she was sick. He died two years later.

After a year of remission, the cancer returned. We knew this would happen eventually, but we didn't know when. The oncologist had explained that this particular cancer would return again and that it would steadily gain ground because the cancer would gradually become treatment-resistant. Sandy was to experience three recurrences of the cancer in all. Even the best estimates of the Memorial Sloan Kettering protocol at the time showed patients not making it past three years. Sandy was determined to beat the odds.

She began yet another round of chemo, and then she was able to return to work. When the cancer appeared the third time, the doctor felt that the cancer had become too resistant to the previous treatments. We had to find something new. I once more began frantically scouring clinical trials around the county, looking for new treatments. Sandy's cousin Hal, a research chemist, helped me scour the lists. A couple of things seemed promising and I grabbed at them as a drowning man grabs at passing branches. Although laboratory rats developed full remission by using these treatments, Sandy did not.



Another round of the old chemotherapy produced a brief respite, but the cancer soon returned for yet a fourth time. As Sandy's oncologist gave us the news, I broke down in sobs. There was nothing more that modern medicine could do for her. I was finally forced to face the fact that Sandy was going to die.

Sandy's oncologist suggested it was time to consider home hospice care. She suggested Hospice. By this time, I had taken full leave from work (Gods Bless the Family Leave Act). But since Sandy needed care 24 hours a day, Sandy's sister, Marian, took leave from her

job as a speech therapist in Los Angeles and came to help me during the final weeks. We took turns taking care of Sandy in shifts. Additionally, friends and neighbors pitched in to help as well. Neighbors in the building where we lived cooked wonderful meals for us. They were compassionate and helpful in many ways.

Marian and I were both sleep-deprived. It now took two of us to move Sandy for even the smallest things. Sandy seldom slept; she was taking a lot of steroids, which kept her brain swelling down, but which also kept her awake. Night and day seemed to merge together in my consciousness; I felt like a zombie. My own major depression, which had plagued me for years, returned. It became increasingly hard for me cope with my depression and to do what I had to do for Sandy. With additional medication, I was able to keep plugging away.

Sandy's body had failed her, but now her mind began to be affected. A kind of dementia set in, and her short-term memory was damaged. She could watch *Wheel of Fortune* and *Jeopardy* and easily guess the answers - but she could no longer follow the story line in her favorite dramas. Sandy could not write or handle a pencil now, so Marian and I would read the New York Times crossword puzzles to her, and she would dictate the answers. She now had trouble recognizing the friends who came to see her. I began to try to discourage Sandy's friends from coming to see her - I didn't want them to see her like that. She had always been a super-competent person who everyone looked to for leadership, and I couldn't bear for people to see her. In retrospect, I know that I was wrong. This was my problem - not Sandy's. She was happy to see whoever came, even if she couldn't remember their names or how she knew them. I worried about inconsequential things; probably hurting many feelings in the process.

Finally, it became clear that Sandy was in her last days. She could no longer eat or move. Marian and I had to shift her around in bed to protect against bedsores. Her breathing became labored. Marian and I now both sat up nights at her bedside, keeping vigil. We sat there in the silence listening to her increasingly labored breathing. Finally her breathing

stopped. I sat with her for about an hour, tears streaming down my face. However, we still had work to do: the hospice people had to be contacted, relatives had to be called. Marian and I threw ourselves into our tasks. Sandy didn't want a funeral, but she had made arrangements to donate her body to medicine. I buried a lock of her hair at labor leader Elizabeth Gurley Flynn's gravesite at Waldheim Cemetery in Chicago. Sandy had known Elizabeth and considered her a mentor.

Sandy's relatives and friends in Philadelphia began to organize a memorial there, and I began to organize one in Chicago. Hundreds came to the memorial in Philadelphia. More than a hundred came to the meeting in Chicago. Newspapers in both cities ran lengthy obituaries.

Three days after the Chicago memorial, the Human Resources Department called and told me I had to come back to work. I dragged myself back in. Copies of Sandy's obituaries were posted all over the office and people were extraordinarily kind. (Well, not everyone was kind, however. Some evangelical Christians dropped by to warn me that, while Sandy was no doubt roasting in hell, I still had a chance to redeem myself).

During the previous years I had been totally task-focused, drawing reserves of energy from God knows where. This finally took its toll on me. I worked for about two weeks and then collapsed from exhaustion. The depression that I had kept at bay finally overwhelmed me. Mentally, I was reliving Sandy's last days over and over. My psychiatrist diagnosed Post Traumatic Stress Syndrome. It was another two weeks before I could face work again.

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In the fall of 1993, right after I finished my MSW, I entered the Ph.D. program at Jane Addams College of Social Work. By the end of 1996 I had finished my PhD and received my LCSW. As an MSW student I had taken the usual courses, including death and dying. I understood the various stages of dying indicated by Dr. Kubler-Ross (1969, 1974), but nothing had prepared me for a struggle like this. I was on a constant emotional roller

coaster, going from heights to depths in rapid succession as we went through the stages of remission and recurrence. Oh yes, I knew intellectually - but nothing had prepared me for the frantic, emotional ups and downs, then having to come to grips with Sandy's death. Fortunately for me, I had a lot of help. I am particularly grateful for the aid of Dr. Nicholas Christakis (1999), a noted specialist in palliative care, who was Sandy's physician. His compassion and advice was a blessing to me.

What I have learned is that Social Workers need to learn to ask for help and to accept help. That was hard for me because I thought I should have all the answers. After all, I was a Licensed Clinical Social Worker.

The most important factor in this story is Sandy's incredible resilience. I think the fact that she lived five years with this disease, when the odds said she couldn't do better than three years, is testimony to this. Furthermore, until her last year, she was able to function at her demanding job, play a role in community affairs, and enjoy life.

Sandy's experience caused me to reexamine some of my own assumptions about my practice. I began to realize the role of resilience, and our own hidden abilities to withstand trauma and loss. I learned, from a client's perspective, how important it is to be involved in the process and not merely a recipient of services. The ability of a client to participate and exercise self-determination was no longer something I read about in social work text books. I learned how enormously empowering and healing it is to be involved even if the outcome is not so good.

This experience was the beginning of my break with the "medical model" which I had embraced so thoroughly in my early practice. My work was with persons diagnosed with Schizophrenia and other serious disorders. I found myself locked into practicing a deficit model, where I was focused on the client's disorder and not the client as a whole person. I focused on clients as chronically hopeless, with little or no chance of recovery.

Sandy blew these assumptions out of the water. Certainly Sandy was more than her disease. And if Sandy was more than the sum of her problems, then what about my clients?

Sandy certainly had enormous inner strength and resilience, but she also had other resources outside herself that she could draw upon: family, friends, wonderful medical care and a comfortable middle-class life. I began to ask myself what untapped inner resources I was missing with my clients. Obviously they were surviving on the street and that required a lot of skills, strengths and initiatives that I wasn't paying enough attention to. How could I find those strengths (De Jong & Miller, 1995)? How could I help to combine those strengths with other resources available in the community?

Sandy and I were atheists, but I saw in her struggle a kind of spirituality. (She would not approve of my characterization.) I began to ask myself about the role of spirituality in recovery and its place in client resilience. I began to ask myself how I had mobilized resilience in myself, what internal forces I was able to draw upon. I don't credit myself, but I do credit those friends and family who helped: those who cooked us dinners, who ran errands, who made generous donations while I was on leave from work, so that I could take care of Sandy and still pay the bills. Sandy's sister Marian was a tower of strength for me. I hope that I was for her.

Today I have opened myself up to new theories and new approaches that are based on strengths and resilience. I look at clients (and now my students) in new ways, looking for strengths to build upon.

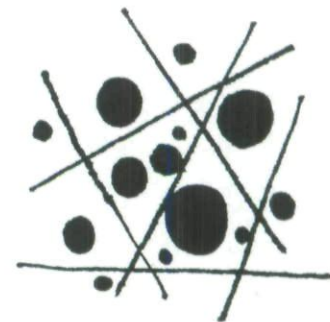
I hope that my clients and my students benefit as well.

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James Williams, Ph.D., is an Assistant Professor at the Savannah State University, Department of Social Work. Comments regarding this article can be sent to: jamesw@savstate.edu



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