

Luck of the Draw

Conrad Valentine

The year 1999 marked an anniversary of sorts in my family. In October 1969 my mother suffered a major stroke. I was 19 and had been attending college for one month. I am the eldest child and the only male. My sisters were 16 and 17 at the time. Our parents had separated when I was three but for some reason had never divorced. We had no contact with our father.

My mother was released from the hospital two weeks after her stroke. She was not paralyzed but was robbed of effective speech. She received no speech therapy, drug therapy, special diet, or follow-up of any kind. No one asked what type of home situation she would be returning to. I didn't talk to a single doctor or social worker.

My sisters and I were completely unprepared for dealing with a stroke patient. We knew nothing about how a stroke affects a person's mental health. Our ordeal would have been more tolerable if someone had just taken us aside and explained in simple terms what exactly a stroke is and what after-effects to expect. If we had known that "crying jags" were a normal part of poststroke behavior, we could have adjusted ourselves to them.

There were other behaviors that we should have known about, too, such as the anxiety attacks and suicide threats. Had we been forewarned about these behaviors, we could have taken measures to prevent them or to seek treatment for them. These behaviors were so frightening and unpredictable that one of my sisters moved out of state; she was practically driven from our

home. After many difficult experiences, my other sister got married and also moved out of state.

I freely chose to stay home and take care of our mother. After I finished college I learned some manual skills so that I could have some flexibility in dealing with my mother's illness. A white-collar job that required long hours or travel was out of the question. I was afraid to leave my mother alone. I never knew when I went to work in the morning whether she would be dead or alive when I got home.

What I found even more amazing was that on some mornings she could be the woman who raised me, and then she could be suicidally depressed the same afternoon. Some mornings when I woke up, I would find her hovering near my bed, saying she did not want to go on living; by afternoon she would be fine. On days like that I would stay home from work on suicide watch. I came to the conclusion that I would not take her threats seriously until she made what I considered to be a genuine attempt to kill herself. I knew I was playing a dangerous game, but no one else wanted to play, and I had to make up my own rules.

Suicide threats and anxiety attacks were not the only problems I had to deal with. I encountered what I later realized were "mood swings." My gentle, churchgoing mother could become violent over almost anything. She would exhibit what I called "irrational anger." She would become angry over events that happened decades ago. Any mention of these events could create a cycle of mood swings that might last hours, days, even months. Another behavior that could tip the balance and send her into a depressive state was unexpressed anger. If someone or something made her angry, she would grit her teeth, her face would flush, and

her eyes would bug out. This is a look I can never forget.

I had my mother committed to the state mental hospital for short stays during the early 1970s because of her violent rages. Unfortunately, when she was released she was even more violent. I had assumed that she would not be released until her condition was stable. I had faith in the doctors and their prescriptions. My faith was misplaced. My most distinct memory of this period is of my mother being very fat, with her eyes all glassy and bulging. I don't remember how long she took her pills; I just remember that they didn't seem to do her any good. No mental health professional ever explained anything about these drugs to me. I simply did not know what to do next. I decided to "sit tight" and wait for the next crisis. I did not have a long wait.

My mother's father died in 1983, and his death plunged her into a severe depression. She threatened suicide and went on a "crying jag." Her eyes were glassy and bulged out of her head. She had a "1,500 yard stare." The only thing I knew to do was to take her to our family doctor. I believe he was an able physician who knew nothing about mental illness. He took her blood pressure and temperature and pronounced her normal.

The solution to my problem came from an unlikely source—my mother's best friend. The friend had mentioned in passing that her brother had been helped by a psychiatrist at a local mental health center. Having nothing to lose, I made an appointment. The psychiatrist was a wonderful man. I was allowed to sit in the same room as my mother during her interview with him. He answered my questions calmly and rationally. It had taken me 15 years, but I finally met a mental health professional worthy of the name. That was in 1984.

The previous 15 years had been the

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worst years of my life. Now, suddenly and unexpectedly, I felt a profound sense of relief. To this day I wonder why no one simply made a referral to a psychiatrist. My mother was placed on antidepressant drugs, and her condition improved greatly within weeks. I continued to care for her, but it was easier. The psychiatrist had told me about signs of increasing depression to watch for, and when to take her to the center for additional treatment.

I feel the mental health system could be greatly improved by someone appointing a person to act as a liaison between "the system" and the family. All I ever wanted was for someone from the mental health system to talk to me, after my mother's stroke in 1969 and especially when she was committed in the 1970s. Anytime I volunteered to help with her care, I was told that my mother was the patient. I was the only adult who lived with her, but I had no role to play in her recovery. I always felt as if I was caught in a web woven by well-meaning professionals.

I knew from my blue-collar experience that if I was frustrated in trying to perform some aspect of my job, I should find another way to get the job done. In an attempt to understand my mother's condition, I began to pay more attention to articles on mental health in the newspaper. This practice marked the beginning of my understanding of my mother's illness.

In 1995 I attended a public lecture at my local hospital on the topic of mental illness and the family. At first I was reluctant to attend; I did not want to hear another word about mental illness. At the lecture several family members related their experiences with the mental health system. Their experiences paralleled my own. For me the most interesting part of the session was a talk given by a prominent local psychiatrist. He delivered a short speech on the history of mental illness in the United States and Great Britain. He concluded his speech with the words, "Before 1976 we doctors did not know what we were doing."

After living with my mother's mental illness for more than a quarter century, I thought I was beyond being shocked. I was wrong. The doctor's

lecture stunned me into examining my own understanding of my life.

I had always perceived myself as a somewhat controversial figure within my own extended family. I was often encouraged to abandon my mother to "the system." I was told many times that I was wasting my life. After hearing that lecture, I felt vindicated. I had made decisions the psychiatrist said were correct. I had taken my mother's suicide threats seriously when everyone else denied the possibility of her acting on them. I had

learned to recognize the symptoms of depression and mania. If exposure to a particular stressor would precipitate a depressive state, I isolated her from that stressor.

Even though I have no formal training in mental health therapy, I feel I contributed significantly to my mother's well-being during the many years I cared for her. She has lived in a nursing home since 1998, and her care is well managed there. For the first time in my life I am living alone, and my own life is good. ♦

MANAGED CARE

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Challenge to the private sector

As part of the political process, public-sector purchasers expect to be called to account for their decisions and policies. Wise public purchasers require the carve-out programs they contract with to behave like public agencies. This requirement entails active interaction with consumers on developing, implementing, monitoring, and revising managed care policies. When it works well, this kind of participation can result in better policies. As important as it is to have substantial consumer presence throughout the management process, what creates legitimacy is the influence consumers exert on the quality of managed care policies and practices, not simply the participation of specific numbers of consumers.

Employers and other private purchasers do not have the same formal accountabilities as public purchasers. However, the national backlash against managed care shows that the public is not satisfied with leaving accountability to market forces alone. Private-sector programs must also seek legitimacy through accountability for reasonableness. They should look to the best public-sector programs to learn how to involve consumers in this enterprise. Future columns will explore this topic in detail. ♦

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