On the Receiving End of Social Work Services

This narrative chronicles a family tragedy which served to transform my understanding of social work. My years of experience as a social work practitioner and educator failed to prepare me to be a recipient of service. I never knew what it felt like to be a client until my father committed suicide.

by
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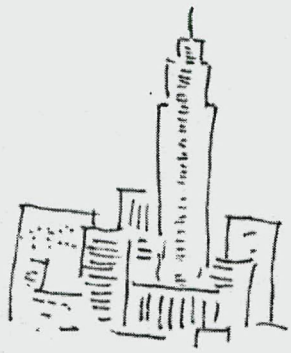


Overture

Some months ago I had a painful but profound experience. Painful because it involved the untimely death of my father. Profound because it gave me a significantly deeper and more intuitive understanding of social work.

One Thursday morning in January, I received a phone call from my step-mother, Peg, informing me that my father had jumped ten stories from the balcony of their New York City apartment to the sidewalk below. Miraculously, he had survived the fall, which had been partially broken by the branches of a tree. My father had been rushed by ambulance to the emergency room at Mercy Hospital, just several blocks away. He was in the process of being admitted. Peg was calling his three children, as well her own daughter Eleanor, so that we could come to New York as soon as possible.

By the time I got to New York (the cab ride from LaGuardia Airport predictably taking longer than the plane ride from Maine), it was almost evening. I went straight to the hospital where my father had finally been admitted to the intensive care unit. Apparently everyone—from the police, paramedics, and ambulance drivers to the nurses and doctors—was amazed that a 74-year-old man could have survived such a fall. The news was far from good, however. My father's body was badly broken; he had sustained multiple, severe injuries and was paralyzed from the chest down. During his brief periods of consciousness, he had begged and pleaded with the paramedics, the nurses, the doctors, his wife to allow him to die.

My father, a retired professor of some renown, had a long history of depression. Most of his life the depression was in remission, never really interfering with his professional career. Although earlier depressive episodes had consistently failed to responded to medication, they had always been vanquished by electro-convulsive therapy (ECT). This most recent episode had been different. My father had been severely depressed for well over a year, increasingly unable to speak on the phone, read, or even concentrate on television. All of the myriad new anti-depressant medications that had become available since his previous depressions had been tried. None had any impact on his deepening despair. Finally, the doctors again resorted to ECT. This time, however, my father's depression proved more powerful than electro-shock.

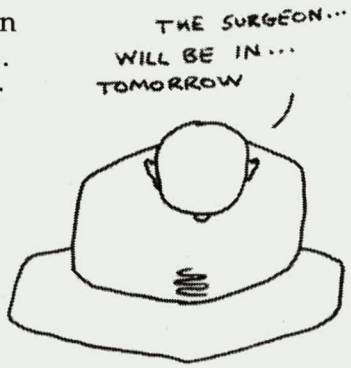
There was no improvement. By year's end, there seemed little reason for optimism. He had clearly given up.

First Movement

When I arrived at the ICU, I saw my own fears and sense of horror reflected on the faces of my family members. The patient in the bed was unrecognizable. He was barely conscious, heavily sedated, and bandaged up to the neck. He was attached to a respirator. A monitor displayed his vital signs in neon purple, yellow, red, and blue. Tubes were taking liquids out of his body. Other tubes were putting different liquids in. I had worked as a hospital social worker for many years. The various technological paraphernalia, their constantly shifting lines and periodic beeps, did not really faze me. My father's appearance did. I was told that the attending physician was expected shortly.

The doctor, a Jewish man in his mid-sixties, was brusque and authoritative. He directed most of his comments to my father's wife, despite her stated preference that he speak with all of us. The bottom line was that my father was lucky (!). He would most likely survive his "fall," albeit as a permanent quadriplegic. I thought to myself, "This is the ultimate nightmare, to be severely depressed and want only to die but without the physical ability to make it happen." A glance of understanding passed between my sister, Sara, and me. I think this was the moment where we both stopped hoping for my father's recovery.

The doctor was still issuing pronouncements. My father would be scheduled for a major surgical procedure to stabilize his back, probably the following week. This surgery would not improve his overall condition but it would enable him to be sat up and fed, making it possible for him to be cared for at home with around the clock help. We were told that the surgeon would meet with us the next day to further discuss the surgery. We raised the question of whether surgery so soon was really such a good idea, but the doctor merely repeated his statement that the surgeon would be speaking with us. Having had little input into that consultation, we sought out the chief resident, an Asian woman in her twenties. Her demeanor was considerably more empathic than the attending physician's. She seemed to understand our growing confusion about the efforts to save my father's life, given his condition, when he had been so specific about his desire to end it. Despite her apparent understanding, there seemed to be nothing she was willing or able to do to intervene. She repeated the mantra that the surgeon would stop by tomorrow afternoon to answer our questions.



Second Movement

Friday morning found Sara, my half-brother, Simon, and me having breakfast at the coffee shop near the hospital. Peg and my step-sister, Eleanor, were at my father's bedside, maintaining the vigil. For the first time, my father's three children gave voice to the unspeakable: Should my father be kept alive when he wanted so much to die? Shouldn't we , who knew better than anyone never to cross him, respect his final wishes? The doctors and nurses were mobilizing all their efforts toward keeping my father alive. Was this what we wanted, or should we persuade them to allow him to die? Couldn't we, as his family, refuse medical treatment on his behalf? Otherwise, what kind of a miserable life sentence were Peg and my father in store for?

We knew we had to talk all this over with Peg as soon as possible, to let her know what we were thinking and gauge her reaction. We needed to include Eleanor in the discussion as well. The topic of allowing my father to die felt scary just to talk about, even among the three of us. We had initially experienced an enormous sense of relief upon learning that his suicide attempt had been unsuccessful. Our first reactions were similar, "Oh please, let him survive this!" It seemed as though many days had passed since we had first received the shocking news...

actually, it had been about 24 hours. I awaited the discussion with Peg with considerable trepidation.

We spent the rest of the morning in the hospital, watching the respirator breathe for my father. At lunchtime, we went back to the apartment. I don't remember which one of us first broached the subject of allowing my father to die. Neither Peg nor Eleanor seemed shocked that we had been discussing this. Perhaps they had had a similar conversation. Peg took seriously my father's wish to end his life, although she was clearly uncomfortable talking about hastening his death. She said, in a strained voice, "You all have to remember, I am the one who will have to live with this decision on a daily basis. I need time to think it over, and I need to talk to him about it." She also wanted to discuss the situation with an old and trusted family friend, a physician who had been my father's closest friend since childhood.

We returned to the hospital after lunch and met with the surgeon, another aging white man. At one point in the discussion, Peg interrupted the doctor's detailed description of the planned surgical procedure and questioned its necessity. She explained that her husband had been so depressed and so determined to end his life that she was beginning to question the elaborate efforts to keep him alive. The surgeon acknowledged that he would probably be asking the same questions if this was his family member but that the hospital had legal and ethical obligations to keep my father alive. He did mention several possible courses of action for her to consider and clarified that either her or my father's consent would have to be obtained before any surgical procedure could be done.

Friday evening, Peg called my father's childhood friend and filled him in on what was transpiring. He strongly supported the idea of allowing my father to die. He urged Peg to act immediately in informing the hospital staff of the family's preferences, warning her that they would initiate all kinds of heroic measures if she did not. He assured her that this was the right thing, the caring thing to do for my father.

Peg returned from the phone call galvanized. It seemed as though she had wanted to make this decision all along but had needed support and encouragement from several quarters to convince herself that it was the right decision, motivated solely by concern for her husband. She still wanted to talk to him, if possible, and make sure he had not changed his mind, but she acknowledged that he had made his preferences very clear. The rest of us were relieved, if a bit stunned by the rapidity of her decision. We agreed to persuade the hospital staff to cease their efforts to "save" my father. For the first time in 36 hours we had a plan, a purpose. We knew that we would get resistance from Mercy Hospital and its staff, but we would proceed as a united front.

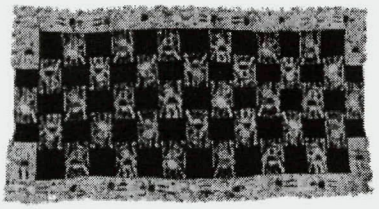
Things were moving so quickly, I felt dizzy and faintly nauseated. I walked out onto the balcony from which my father had jumped, a place I had been consciously avoiding. I needed to be alone with my thoughts for a little while. I felt strangely close to my father standing out on the balcony, still very sad but calmer than I had felt all day. I marveled at my family's uncharacteristic unity; it was extremely reassuring. I felt convinced we had made a good decision, we were doing the right thing. After a while, the frigid January air sent me shivering back into the warmth of the living room.

Third Movement

Early Saturday morning, we went, en masse, to the hospital. My father was still heavily sedated and seemed unaware of our presence. We asked that the attending physician be paged. Fortunately, he was already in the hospital and came within the hour. Peg spoke firmly of our resolve to allow my father to die and detailed our family friend's specific instructions (including canceling the surgery, removing the respirator, and signing a "Do

Not Resuscitate" order). The doctor became annoyed, said he could not remove the respirator until my father could breathe on his own, and indicated that he would have to consult the hospital's attorneys and medical ethics board before considering our requests further. He left the room abruptly. Peg looked deflated. Nothing would or could happen until after the weekend. Ethics boards? Lawyers? This was all getting much too complicated and we had no one in our corner. I suggested we contact the social work department first thing Monday morning. My family agreed.

Needing an excuse to leave the hospital, I volunteered to go to the supermarket to replenish our supplies. When I returned to the hospital, my family was gathered around yet another physician, a white-coated, Caucasian woman in her early forties. Her demeanor, affect, and communication seemed completely different from that of the other doctors. She was commenting on how much strength it must have taken for us to come to our decision, how much we clearly supported each other and wanted what was best for the patient. She concluded the discussion by saying that she would try to help us get through to the attendant or find other members of the medical staff who would be more sympathetic to our position. She left, saying she would be in the hospital and reachable by page all day. I stood just outside their circle, amazed. When she left I exclaimed "That doctor was wonderful, who was she?" Sara replied "She isn't a doctor, she's the social worker." Recognition dawned. The white coat and Saturday work schedule had obscured what now seemed obvious to me. Of course she was a social worker!



Crescendo

I raced down the hall and caught up with the worker, introducing myself and my social work credentials. She identified herself as Diane Rivers, a worker at Mercy Hospital for six years. We chatted a bit. She spoke openly about Mercy Hospital's squeamishness about my father's case. Apparently, there was already much concern among the lawyers and higher level administrators. I expressed surprised that they even knew about the situation so soon. She explained that the phones had been humming all morning; this was apparently a very new situation for this Catholic hospital. She saw the hospital as having a long way to go in understanding the many meanings of mercy.

Diane asked me a few questions about my family, reiterating her earlier comments about our strengths. She shared her observation that from our appearances, my siblings and I were presumably the progeny of several marriages. I briefly described our family structure and its complexities. I shared my realization of the previous evening that the current crisis seemed to be bringing us closer together than we had ever been. She told me she often saw that happen in medical emergencies, that this could be something important to build on. The conversation turned to the problem at hand, the resistance of the hospital system to carrying out our wishes. Diane told me that a psychiatric consult had been ordered to determine my father's competency to refuse medical intervention and gave me the name of the psychiatric resident she thought would be most sympathetic to our plight. She said she would try to arrange to have this resident assigned to my father's case. She also repeated some of the suggestions she had made to my family in terms of overall strategy and renewed her commitment to advocate for us. She handed me her card, looked me in the eye, and left.

I sat down, letting waves of intense feeling wash over me. I felt understood, appreciated, and valued. I also felt bolstered, respected, and acknowledged as an individual and as a member of a viable, self-determining family unit. I felt joined in the battle against the bureaucracy. Finally, someone shared our perception of the situation and was on our side. Moreover, this was not just anyone; this was someone with perceptivity, training, experience, and knowledge of the hospital system, someone with some clout. I returned to my father's bedside, feeling clearer and stronger.

Finale

Events followed quickly. The psychiatric resident appeared but was unable to rouse my father. She took the family into a private room and interviewed us at length. Seemingly convinced of our unity and our desire to do what was best, she recommended that the attendant place a "Do Not Resuscitate" order in the chart. The attendant was paged and conferred privately with the psychiatric resident. The attendant apparently was still uncomfortable acting solely on the family's wishes. He wanted to again try communicating with my father, who had not had any pain medication for a while. He shook and shouted at my father and finally managed to rouse him. My father briefly opened his eyes. The attendant ascertained that my father seemed to know where he was and why. He asked my father to blink once if he wanted medical care withheld, if he did not want help to remain alive. My father blinked once, unmistakably. I felt the tension ease out of my shoulders. There was no further productive communication but the attendant seemed satisfied. He explained to us and to the psychiatric resident that he just had to be absolutely certain before he could withhold medical treatment since that went so deeply against the grain of his training and experience.

The attendant wrote orders for my father to be weaned from the respirator and for a "Do Not Resuscitate" order to be placed in the chart. There would be no surgery. Other minor procedures that had been ordered were cancelled. My father would be given nourishment, hydration, and pain medication, nothing else. The doctor warned us that he might continue to live like this for several weeks. Once off the respirator, he would be moved out of the Intensive Care Unit.

Diane stopped by before leaving the hospital for the day to see if we needed anything. We discussed the day's events. She let us know that this had been a pretty big deal for the hospital, that they had been concerned not just about medical ethics but also about potential lawsuits from one or more family members should we come to regret our decision and blame each other and the hospital. We had apparently impressed the psychiatric resident and the attendant as to our unity and resolution. My father's ability to communicate his wishes directly to the attendant had, of course, been pivotal. Diane suggested that we remember this if we should ever question our own decision making, since the final decision had indeed been his. We thanked her for all of her help during this very difficult and exhausting day.

The next day, Sunday, my father was weaned from the respirator. The "Do Not Resuscitate" order was placed prominently in his chart. Sunday afternoon, he was moved to a semi-private room where he was kept heavily sedated on pain medication, which had the side effect of suppressing his respiration. Monday night, my father experienced severe respiratory distress and died.

Coda

One of the few positive aspects of this terrible ordeal was my experience as a social work client. Why did this very brief encounter with the hospital social worker feel so powerful? She was highly competent but really not all that unusual. I had utilized similar skills in my own practice with clients and I had taught hundreds of students to practice, as she did, from an empowerment-oriented perspective. Diane embodied the social work values and skills I had been teaching and preaching for many years: tuning in, starting where the client is, conveying empathy, identifying and working with strengths, providing information, mobilizing resources, and offering to intervene on the client's behalf while acknowledging and building on the expertise of the client system. She moved easily between the roles of supporter, clarifier, educator, advocate, and change agent.

As client, I experienced these skills and attributes in a profoundly different way than I ever had as practitioner, teacher, or researcher. What had previously been a series of concepts and constructs became a lifeline, a source of help, a promise of partnership. I gained a very special understanding that weekend of what social work could be.

Some time after my father's death I wrote a letter to Mercy Hospital's Director of Social Work. It read, in part, as follows:

...those days were among the most difficult my family has ever faced. Trying to advocate for my father and for ourselves with various medical personnel proved enormously difficult at a time when we were feeling vulnerable and in need of no additional challenges. We were confused, overwhelmed, and frightened.

In the middle of this nightmare, Diane Rivers appeared. The rapidity and accuracy with which she assessed the situation, grasped the complexities of our family composition and dynamics, and tuned into our needs was breathtaking. She understood that we needed support rather than clinical intervention, information rather than answers. She heard our frustration, respected our concerns, and advocated for us with the staff. She also provided us with the necessary knowledge in order to advocate more effectively on our own behalf. In short, Diane's skilled interventions made an unbearable situation significantly more endurable. We finally had someone who was on our side, who understood what we were going through, and whom we could trust...After a quarter of a century as a social work practitioner and academic, I thought I understood social work practice as well as anyone, but I had never before been on the receiving end. I now realize how different experiencing social work is from that vantage point. Diane helped me to see social work from a wholly new perspective that I cannot adequately put into words. It has to do with the incredible relief and groundedness you feel when your whole world has suddenly turned upside down and you finally discover someone who understands and is on your side, someone who respects what you want and is able to help... □