

Over the last quarter of a century, the field of renal replacement therapy has developed so that what began with questions of survival slowly evolved toward explorations into quality of life. This parallels my own development as I adjusted to creating a life for myself while managing kidney disease and all its effects.

I began dialysis treatments in 1975 in New York, when the field, like me, was no longer in its infancy and still had much to learn. I had acquired a kidney infection as a young child and had experienced frequent bouts with colds, flu, and bronchitis throughout my early years. It seemed to me that I was on antibiotics more often than not. A kidney biopsy performed at age 11 revealed what my family had been dreading. A low protein diet and Imuran therapy were begun in an attempt to stave off the inevitable, but within four years, my kidney function deteriorated to the point where I required dialysis treatments. My first fistula surgery occurred amid a thick haze of shock and disbelief. All the while, I was struggling to hold onto a sense of normalcy and was unable to discuss what was happening to me outside of my family. It was all so unbelievable because I didn't feel as sick as people were indicating I was. Looking back, I realize that I owe a large debt of gratitude to a thoughtful Israeli nephrologist, Dr. Haim Boikus, who insisted that I begin dialysis while I was still relatively well. The wisdom of that decision escaped me at the time. I am so thankful, though, that my dialysis beginnings did not occur in a life-or-death emergency situation, as is the unfortunate case with so many.

This dialysis business has got to be temporary, I thought. "Don't worry," the doctors assured me. "You'll get a kidney transplant and everything will be fine." Famous last words. Within three months I received the awaited kidney transplant. The dialysis treatments were easy compared to that transplant experience. I was completely unprepared for the nightmarish

experiences of the next few months. Suffice to say, I returned to the dialysis unit a shell-shocked war veteran.

A survivor's determination that I didn't know I had kicked in. I began to realize that the doctors were far from the final authority on all matters and that I could make a difference in my own care. I learned an invaluable lesson during that time. My second fistula was very weak, and I was forced to endure multiple infiltrations with each treatment. I lived in fear of each dialysis session. The residents were constantly being called in case I needed a femoral catheter inserted. I felt the need to draw the line. Things seemed once again to be spiraling out of control. In a quiet and determined voice, I announced my intention to put in my own needles. This didn't sound very realistic to the staff, because at the time I couldn't look at the dialysis machine squarely, let alone at the 16-gauge needles. However, with the patience and guidance of two extraordinary nurses, I learned how to insert my needles. There were no more infiltrations and my fistula grew stronger. I learned that I could protect myself. The quality of care I had received ranged from inept to outstanding. I realized I did not always have to be at the mercy of those who tended to me. Armed with this knowledge, I decided I would leave New York to attend UCLA, which had been my dream.

In California I threw myself into my studies. I graduated with a degree in psychology and went on to receive a master's degree in special education from the University of Southern California. I began work as a language and speech teacher with deaf children, then moved on to become an early intervention specialist, and then into my current position in teacher education, training teachers of the deaf.

Meanwhile, I dealt with aluminum toxicity (another proof that dialysis was far from being an exact science) and ongoing fatigue. I still held on to the hope of transplantation and was on the list for several years. In 1986, during my first year of teaching, I was called for a second transplant. At the time, cyclosporine was the new drug that was raising everyone's hopes. Unfortunately, it didn't do the trick for me. The kidney went into shock, never began working, and my body rejected it. I returned to my dialysis unit with a nonfunctioning transplanted kidney. After my body launched a second rejection episode, the kidney was removed.

It was suddenly time to do some serious thinking about my future and the world of dialysis. I had maintained the perspective that dialysis was a temporary situation that I had to endure until I received the transplant that would give me a normal life. Now was the time to take stock. Although no one expressed this idea to me directly, during the first several years

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of dialysis I struggled with my doubts. What's the point? After all, things must be pretty bad if I'd reached the "end stage" of renal failure. However, it was my survival instinct that made me realize that end-stage renal disease should not signal the end stage of life. Granted, the first few years had been difficult, but as time passed my health stabilized, and I began to wonder more about my potential. Could it be that good for the rest of my body to lay in a chair for 12 hours a week while my blood was cleaned? No one in the dialysis unit ever discussed my overall physical health with me. The focus seemed extremely narrow. During hemodialysis sessions I began experimenting with simple movements of my legs and my unoccupied arm. Unfortunately, the nurse in charge of my station was horrified and insisted that I stop. She stated her concern that my blood pressure would drop, and besides, she didn't seem to appreciate that I had encouraged the participation of two of my companions in the chairs across from me. My little exercise routine had apparently created quite a stir. This wasn't my first run-in with the status quo of the dialysis unit. I had managed to resist reuse of dialyzers (no one could convince me that there were no long-term ramifications) and was not interested in high-flux dialysis (why rush through the treatment and place unnecessary strain on my heart?). I had seen low expectations placed on patients over the years, and the sometimes dispiriting environment was depressing to me. Why did some staff speak to adult men and women as if they were children? How could people take full responsibility for their health if they were continually nagged about their eating habits as if they were errant schoolchildren? For a long time I approached the dialysis unit as simply a place I went to three times a week. I would come in, make my rounds to shmooze with the other patients, and put myself on. But now, the schedules were tighter and more shifts were being created with more people per shift and fewer nurses. I was seeing more and more things that I didn't like.

For years, I had required two units of blood every four weeks to maintain a hematocrit of 17% – 20%. I knew I had to make a change. I began to investigate peritoneal dialysis (PD). This was a modality I had never before considered because I had only seen it used as a last resort in the 1970s when no hemodialysis access was available. I had heard very frightening stories of life-threatening peritonitis, and it seemed too risky. But I reasoned that this was a decade later, and I felt strongly that I needed to make a move. I researched a few different facilities that offered PD and asked a lot of questions. I was very impressed with the Los Angeles Dialysis Training Center for a number of reasons. They placed a high priority on the patient's overall health and individualized dialysis prescriptions for maximum benefit. The head nurse, Doris Holmes, served as an extremely knowledgeable guide into the world of PD. She patiently and thoroughly reviewed all the issues with me. She had a wonderful pragmatic approach and communicated her high expectations. It was clear to me that she believed in PD and its benefits. She helped me work through my hesitations and fears, including resistance to the

idea of a catheter and fear of infection. The idea of a gentle, ongoing form of dialysis (in contrast to the peaks and valleys of routine in-center hemodialysis) that I could do myself at home was really beginning to take hold. My physician, Dr. Frank Strauss, whose conservative and critically minded approach I respected, was in full support of my decision. I made the move.

Within a few months of switching modalities, several things occurred. My hematocrit went up and stabilized (I no longer required blood transfusions), my skin tone noticeably improved, and I experienced an amazing emotional high. I was stunned that I could make such significant improvements and still be a dialysis patient. After more than 12 years of hemodialysis, I felt as if I had been released from prison. Taking care of myself at home gave me a strong sense of control and peace of mind. Center hemodialysis units are built around routines and protocols, and that's a necessary thing. But people, including those employed in dialysis, tend to become lackadaisical over time. It is a rare professional who continues to try to improve once a particular treatment regimen becomes standardized. All too often, completing the chart becomes the sole reason for asking the patient questions. Important clues are overlooked because after a while people stop listening and start performing their duties by rote. And that's when errors can happen. There is, however, a stable force in this scenario. The patient is the only member of the health care team who remains a constant. And it is within this seemingly obvious statement that the key to optimal health care over the long term can be found. It ultimately doesn't matter whether independent people choose home dialysis or if home dialysis develops the most independent patients. The important point is that home dialysis therapy, whether hemodialysis or PD, should continue to be made available and encouraged.

The staff at my PD unit play a critical role in patient outcome. They demonstrate the key factors of providing outstanding support. Thorough patient education by highly qualified nursing staff is essential. What is most important in the selection of patients for PD is that the patient be motivated and willing to take an active role in his or her care. Age, limited formal education, or limited use of senses (for example, legal blindness) should not be used as deciding factors. During PD training, it is imperative to utilize a variety of learning styles. Information should be presented through both visual and auditory means. Abundant opportunities for hands-on practice should be provided. Nursing staff need to view themselves as service providers. They are there to facilitate learning. Twenty-four-hour phone support should be a given, and nurses should be compensated appropriately for this crucial service. Home dialysis involves a trust-building process. Patients need time to place trust in the staff and, most importantly, in themselves. Staff should understand basic learning curve principles. Initially, abundant phone contact should be expected and encouraged. Confidence builds when people feel safe and knowledgeable about their care.

In my own case it's difficult to determine what the primary reason was for all the positive changes that I experienced. Was it the switch from routine hemodialysis to PD or the switch from in-center dialysis to home dialysis? Most likely both factors are significant. I believe that PD gives me a higher quality dialysis and better health. I also know that home therapy gave me a tremendous psychological boost and, ultimately, a higher quality of life. A discussion of modality choices should include information on the potential health and psychological benefits that home dialysis may provide. Although I had managed to accomplish much while on

hemodialysis, it wasn't until I took total responsibility for my care at home that I could comfortably envision a future for myself. Once I achieved some control over my health, I could finally begin to take more risks in life itself.

Editor's Note

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