

Len Andrew

“The prospects for this patient are not good.”

I was 39, with a loving wife and two great daughters, Beth, age 11, and Marcy, age 9. I had been promoted and was working for a terror of a boss with the nickname “Black Jack”. He had caused two attorneys before me to find other work and I felt the pressure. But I did not feel ill when I had my annual physical. Dr. Newman said my blood pressure was high and he ordered more tests. Then he sent me to a kind of specialist I had never heard of before, a Nephrologist. The only words in his report that I remember were: “The prospects for this patient are not good.”

A new world began, with a whole new vocabulary: albumin, serum creatinine, BUN, GFR, hematocrit, fistula, dialysis, transplantation.... I was put on a low protein, low potassium, and low phosphate diet. When I asked the dietician what I could eat, among her suggestions were marshmallows. Diet made little difference; my kidneys were failing.

I hated going to a depressing hemodialysis center three times a week while trying to do my job. When I learned of “continuous ambulatory peritoneal dialysis”, I soon had the training and surgery for a catheter. It was relentless, requiring exchanges of solution every four hours. Each exchange had the risk of infection and had to be done with great care. But I felt better and had a sense of independence. I could take a half hour from my office to do an exchange in the nurse’s office. I could travel with boxes and the bags of solution in the trunk, a bag for an exchange hanging from my rear view mirror while driving.

That summer, I bought a canoe big enough for the entire family. My doctor treated my anemia with blood transfusions. The long-term consequences of this standard medical treatment were beyond imagining.

I learned I had to push my Nephrologist to get me listed for a transplant; he seemed to think I should be content with dialysis. Late in the evening of September 20, 1981, after only eight months on the waiting list, I was called by Montefiore Hospital. A kidney was available from a young woman who died in an auto accident. I went for blood tests to confirm the match and returned home. I slept well that night – Helen was awake most of the night – and had surgery the next day. When Helen saw me up shaving the following morning, she noticed that my face was no longer pale.

Dr. Tellis, my wonderful surgeon, said my kidney failure was idiopathic: “That means the doctor is an idiot and the patient is pathetic”. The only anti-rejection medication available was Prednisone and Imuran, and the transplant survival rate was about 50%. Cyclosporine, the immunosuppressant drug introduced the next year, proved to be toxic and caused kidney failure.

The next summer, we celebrated with a family trip through Europe.

In 1990, when I was offered a position in Tokyo, the company doctor said I was not medically qualified and the medical professionals in Japan were unable to treat transplant patients. He was wrong on both counts. I had his decision reversed, and Helen

and I spent four wonderful years exploring Japan and the rest of Asia. Dr. Iishi was as experienced with transplants as any American doctor and cared for me well.

After we returned to New York in 1994, I learned that the blood transfusions in 1981 had given me Hepatitis C. They did not know to test for the virus at that time. The symptoms of Hep C usually appear about 20 years after the infection; I faced an unpleasant death around the year 2001. There was no treatment then; it was not until 2014 that very effective drugs were introduced. Instead, I am one of the fortunate few who for unknown reasons do not get liver damage from the virus. Among many other wonders, I was able to meet my two grandsons, Rafa, now 9, and Tono, now 8, the day they were adopted as infants in Guatemala, and to know my granddaughter, Gwyn, now 5, adopted at birth in Minneapolis. I have seen Marcy become a dedicated midwife and mother working in the beauty of Taos, New Mexico, and Beth become a mother and a successful writer, consultant, and spiritual director in Minneapolis.

Since my retirement in 1999, I have been privileged to work with many people dedicated to making a difference in our communities and the world. I've been associated with a variety of organizations: the local Y, the Rotary, a pre-school and an after-school program, a mental health care provider, a low-income housing corporation, a continuous care retirement community, an historic cemetery, a Muslim women's group, an international child health foundation, a civil rights organization, a firm providing legal services to non-profits, a group promoting interfaith understanding, and, of course, an organ and tissue transplantation support organization. What a pleasure each of these relationships has been.

Creatinine levels, stable for 28 years, began to increase in 2010, the cause unknown. Again, my Nephrologist just assumed I would go on hemodialysis, although he knew my wishes for peritoneal dialysis and a second transplant. "No one will touch you with Hepatitis C", he said. "You'll be fine on hemodialysis. After all, you already have a fistula." He failed to tell me when my kidney function dropped to a level where I was eligible to be listed. Months later, I spoke directly with the Mt. Sinai transplant team to learn I was eligible and what tests I needed to be placed on the list. I had them done.

This was a period of many disappointments and many joys. I was offered kidneys by two amazing people, Helen and an anonymous altruistic donor. I will always have tears in my eyes when I think of their generosity. But both were told they could not donate. Then a Cardiologist told me that there was a problem with my heart such that he could not certify me for the transplant operation. I began to doubt whether I would get a transplant and could have given up, but I called Mt. Sinai to ask for a recommendation of another Cardiologist. This one said that whatever heart issue I had was most likely due to retention of fluids because of kidney failure. She certified me for the operation. Her diagnosis was reaffirmed by a recent test.

I made my own appointments to have a catheter surgically inserted for the new continuous cycling peritoneal dialysis (CCPD). This is done overnight with a portable machine that fits in the overhead compartment of an airplane. Boxes of solution can be shipped by the supplier. I was able to visit my grandchildren in both Taos and Minneapolis without missing a treatment.

The most unbelievable news was that the Hep C that I thought was a death sentence turned out to be a blessing. There would be no risk to me to get a Hep C infected kidney that few others wanted. The Transplant Coordinator at Mt. Sinai said: "There are

plenty. Wait for a good one.” I waited only four months.

I was listed in New York in September 2010. Since we were celebrating Christmas in Minneapolis, I made an appointment with the University of Minnesota Medical Center to be listed there. On the night of December 21, the day before my appointment at the Center and while we were making our holiday plans, Mt. Sinai called to ask me to come to New York City for tests to assure that the kidney they had was a good match. The donor was a man in his 50s who died in an auto accident near Philadelphia. I made reservations to leave Minneapolis early the next morning. I was at Mt. Sinai at noon, bypassing the normal check-in routines, the match was “perfect”, and I was on the operating table at 4:00 p.m. I was home on Christmas day.

What can I say to express my gratitude? Whatever it may be, it will never be enough. How do you say “thank you for giving me life?” To the donors and their families? To the researchers and medical professionals who have made transplants available to so many? For the love and support of family, friends and community? To the many exceptional non-profit organizations that have allowed me to contribute my legal skills, giving my life meaning? THANK YOU.

Never accept the diagnosis that “the prospects for this patient are not good”. Question authority. Get other opinions. There is always hope.