

Forty Years on Hemodialysis

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(Author's Note: This article was written in stages over four decades. Each stage or section documents my medical status at the time and my evolving attitudes toward dialysis. I've prefaced each section with comments (in italics) written in the present.

INITIAL WRITING — 1970

(This section, written after two years of treatments, may make dialysis seem too good to be true, but it does portray how successful the treatments were for me. Unfortunately, I was largely oblivious to the stress that home dialysis caused for my wife, who had to take care of our daughter, who was only a year old when I began treatments, as well as me.)

Three times a week, I spend six hours¹ of my time in a “health spa.” The benefits are not smoother, younger-looking skin and sinewy, rippling muscles, but continued life itself. I am referring to a spare bedroom that houses a remarkable machine that substitutes for my own failing kidneys.

Three years ago (in 1967, at age 27), I was entering the latter stages of uremia (due to Alport's Syndrome). I had resigned from my job (as a mathematics professor at UCSD), and could do little more than mope around the house and try to conserve what little energy I had left. Even standing for more than a few minutes made me breathless².

Now, except for the time spent with the kidney machine, my life is essentially normal, professionally and socially. I can mow a lawn, shovel snow, paint ceilings, take walks, bowl, dance, dine out, and play with my child—everyday things that seemed forever lost to me. During summers, I play golf and ride a bicycle.

My diet is practically normal, and since the initial dialysis, in June 1968, I have gained 20 pounds. I feel as well as I've ever felt in my 30-year lifetime—perhaps better—because I value all the joys of living so much more today.

¹ With today's more efficient dialyzers, treatment times are now typically three to four hours.

² In spring 1968, my wife and I moved back to Massachusetts, where we both grew up and where our families lived. I secured a position as an Assistant Professor at Boston College without really knowing if I would be able physically to start the job in September. My first treatment was on June 12, 1968. After a few weeks I felt reborn.

Of course, there is still no perfect substitute for a real kidney. Six hours is a long and uncomfortable time to sit in one place. I feel also that this loss of valuable time is a minor professional handicap, even though I often perform certain light duties, such as paper grading, during dialysis. The sessions usually run from about 4:00 p.m. to 11:00 p.m., including cleaning the machine, so I have dinner during the treatment.

There are various side effects to hemodialysis, especially during the first few months of treatment. Many of these, such as nausea, headaches, dizziness, and cramps—not all of which are experienced by every patient—either subside or disappear after a few weeks. New complications may sometimes occur. Those who are so inclined may easily find something to worry about.

After many months of home dialysis, I believe that 90% of the problems the patient encounters can be lumped under the heading “psychological adjustment.” There is absolutely no pain associated with the treatment, nor any sensation of blood entering and leaving the body. But many patients have great difficulty in adapting to the idea that their lives are dependent on a mechanical contrivance. In particular, a great deal of anxiety is attached to shunt care. This piece of plastic³ is an admittedly vulnerable addition to one’s anatomy. It is the patient’s lifeline: a clearly visible symbol of the precariousness of his or her existence. However, I try to think of my shunt in the same way most people think about eyeglasses, hearing aids, or dental appliances. It is only a minor inconvenience. Hemodialysis is only a minor inconvenience—minor, because I never allow it to dominate my thoughts. Minor, because I really do not think of myself as a sick person. Certainly, only those who have been told of my condition would have any reason to think me anything but quite healthy.

Of course, my wife was nervous in the beginning about becoming a dialysis nurse and wondered if she could ever learn all that had to be learned. I was apprehensive, too, but my scientific curiosity was greater than my fear. Now, operation of our dialyzer is a routine matter, which either of us can handle without giving much thought to it.

As for our 3-year-old daughter, she is, of course, too young to understand why her daddy spends three evenings a week alongside that strange machine whose knobs and switches are such fun to play with. Nevertheless, we make no attempt to keep her away from the machine, or from me when I’m on it. She probably thinks that everybody’s daddy has a machine like mine.

³ Nowadays, most patients have an arteriovenous fistula or an artificial vein graft rather than an external shunt.

I believe that returning to work or other meaningful activity is a necessary part of good patient morale. A healthy attitude and a sense of purpose in life go hand in hand. The dialysis patient needs something non-medical to worry about. Feeling sorry for himself or herself is a disastrous state that must be avoided at all costs. Personally, I am much too busy with my mathematical research and teaching to worry about my kidneys—and that is how it should be.

UPDATE — MAY, 1971

(I still seem to be in the “honeymoon phase” in this next update. The advent of the A/V fistula was a godsend.)

It is now nearly three years since my first dialysis. I can state frankly that my attitudes toward this therapy have not changed significantly. My Scribner shunt was replaced by an arteriovenous fistula in my left arm in June 1969. This is a marvelous improvement over the external shunt, for it requires no care between dialyses. Clotting, leakage, and infection are no longer problems, the patient need not be on anticoagulants, and physical activity is not limited for fear of shunt injury.

Admittedly, it was difficult for my wife to master the required needle technique, and the first month or two with the fistula was a trying period. But now she never misses, and I have even learned to make the venipunctures on myself.

I still keep as active as possible and feel quite healthy. My wife and I regularly bike ride around our neighborhood and play golf together (eighteen holes, unless my wife tires after nine). I have played softball, volleyball, and have ice-skated. I have been teaching a full schedule this year as well as an additional evening course. I have had some problems, of course, e.g. two episodes of bronchitis, but all in all we have been very fortunate.

UPDATE — JUNE, 1978

(Five years ago—in early 1973—I put myself on the cadaver waiting list and, after four months, received a kidney from a young victim of a motorcycle accident. After only five days, it was rejected (tubular necrosis) and heroic efforts to save it, including sublethal local irradiation, failed. This was a serious setback. My wife and I were very discouraged. It was especially disappointing to my wife, who had hoped to be finally free of home dialysis.)

Following an unsuccessful transplant in 1973, I began center dialysis. My main reason for transferring from home to center dialysis was the cumulative effect of the stress of

home dialysis upon my wife and daughter (now 11 years old), stress of which I was not fully aware in the earlier years. Although home dialysis is an excellent mode of treatment for many people, it is important to realize that it places a serious psychological burden on the family member who assists in the treatments. The decision to dialyze at home must be carefully considered by both parties—and reviewed from time to time, since the choice of therapy method should not be viewed as unalterable in the future.

My own condition remains quite favorable after ten years of dialysis, and I remain fairly active, although I get out of breath a little easier than in the beginning years on dialysis. Whether this is due to ten years of aging—I'm 38 now—or long-term side effects of dialysis, or both, is hard for me to say. I am not planning a second transplant in the near future, but look forward to one some day.

UPDATE — JULY, 1981

(I was still doing well, although not as well as during the pre-transplant years.)

At age 41, I am now in my 14th year of dialysis and still doing well. I am still teaching full time, have written a textbook, and am doing some consulting work besides. My diet is more or less normal, although my body seems to be a little less tolerant of overindulgence than in the earlier years.

Physically, I am somewhat less active than before and have been paying others to do such chores as lawn mowing and auto maintenance, which I used to do myself. Recently, I began an exercise program of sit-ups and push-ups to regain some of my lost muscle tone.

At my dialysis center, I initiate my own treatments unaided. I am convinced that those patients who take the responsibility for their own treatments (determine and regulate their own pressures, flow rates, etc.) invariably do better on dialysis than those who just sit back and leave it to staff (who vary in competence and experience).

I have been thinking more about transplantation lately and might consider a second go at it one day.

UPDATE — MAY, 1983

(I was naïve to think I would get another transplant, being virtually 100% presensitized, although I still send a tissue-typing sample to the histocompatibility lab each month. I'm disappointed that medical science has not found a way around high sensitivity.)

I have now completed nearly 15 years on dialysis. A little over a year ago, I put myself on the transplant list and am awaiting a 2nd cadaver kidney. Unfortunately, I am highly presensitized⁴, so it may be a long wait. I am still working full time as a mathematics professor.

UPDATE — JUNE, 1988

(Still going strong professionally, but with a little less stamina.)

I have now completed 20 years on dialysis. I have been very lucky, since I've been able to work the entire period. I've carried a full teaching load and published three textbooks. I also manage to do a small amount of consulting and assist my wife with a desktop publishing and word processing business she began several years ago. I look forward to seeing my daughter graduate from Boston College next year.

I'm 48 years old now, so my stamina is not what it once was, but I have no trouble walking or climbing stairs. Giving a 75-minute lecture sometimes exhausts me, especially if I lost a little too much fluid during the previous evening's dialysis treatment. I keep telling myself to exercise more, but I don't seem to be taking the advice.

I am still awaiting a second transplant, but by now hardly with bated breath. Treatment times are down to only four hours now, which is a lot easier to take. I may try high flux dialysis in the near future, which should reduce the time further.

UPDATE — JUNE, 1993

(A medical crisis in November 1992 changed my life forever.)

This month I completed 25 years on dialysis. I switched to high flux dialysis about two years ago and feel this mode of treatment represents a definite improvement, not just because of the reduction in treatment duration (now 3.5 hours for me). Judging by tests that measure adequacy of dialysis, I am quite well dialyzed. I notice that I feel better on Mondays (after a three day interval between treatments) than I used to with conventional dialysis. Neurological problems—I had five surgical procedures for carpal tunnel syndrome during the eighties—seem to be diminished; at least the symptoms of this condition, which is a compression of a nerve in the wrist due to inflammation and scarring, have not recurred.

⁴* This means that I have built up a great many antibodies in my blood that would cause me to reject a kidney from almost anybody but a near -perfect immunological match.

Last summer, my wife and I played golf a lot, and I was able to walk eighteen holes while pulling a golf cart behind me. I am still a mathematics professor at Boston College, although I am currently on a temporary medical leave of absence (see below).

My wife and I recently celebrated the marriage of our daughter, now 26 years old. It was always my wish that I would live long enough to see this. Now I look forward to becoming a grandfather some day.

On November 18, 1992, I developed chills and a fever during my dialysis treatment and was transported by ambulance to the hospital. There it was discovered during exploratory surgery the next day that my pancreas and gall bladder were inflamed, and the latter had to be removed. I had to have a second surgical procedure because of internal bleeding and then ran into other complications, including dangerously low blood pressure. I wound up in intensive care and on a respirator for about 11 days. I very nearly died. After a total of six weeks in the hospital, I began a period of several months of recuperation that is still continuing as of this writing. Needless to say, this episode had profound emotional and psychological effects on me that may well outlast the physical toll. For many weeks, I was no longer in control of my health, but dependent on others. That was very difficult for me.

I hope to regain my strength and resume teaching next year. The support of my friends, family, and coworkers has been invaluable to me.

And of course, words are inadequate to express my gratitude to my wife Susan for standing by me through the difficult times as well as the good, and for always being there when I needed her.

UPDATE — AUGUST, 1999

(I placed myself on disability leave after my 1992 crisis and never returned to teaching, although I have been able to do a small amount of computer-related consulting.)

It is now nearly seven years since my medical crisis in 1992 and over 31 years since beginning hemodialysis. As it turns out, I decided not to return to work at Boston College. After 31 years of hemodialysis, at age 59, the side effects of long-term hemodialysis, especially bone disease (renal osteodystrophy), have greatly limited my mobility.

In January of 1997, I fell and fractured my right hip. It was then that I learned about a condition called beta₂-microglobulin amyloidosis, a serious problem for nearly all patients who have been on dialysis for more than a decade. This type of amyloid is a protein

substance with the consistency of week-old chewing gum that can deposit in bones, joints, the hands, and other places in the body. In my case, it weakened the hips and eroded the rotator cuff in my right shoulder, among other things.

The hip was repaired by pinning with large screws. Unfortunately, the screws did not hold, and so in September of 1997 I had a total hip replacement. That worked beautifully for the better part of a year. It felt like a normal hip! Then I began to have hip pain after walking or standing for more than a few minutes. It is possible that the prosthesis is loosening (a hip arthrogram was inconclusive). I have been using a cane for several months.

Recently I began having lower back pain, and it was discovered that I need to have spinal fusion surgery, which is scheduled for the end of this month. I also learned that my hip pain may, at least in part, be caused by nerve compression in the lower back, so I am hoping that the back surgery will alleviate much or all of the hip pain. If so, I hope to return to my former mobility.

Although physically limited, I have kept active mentally and socially. I visit my grandchildren, Alexandra, 5, and Brett, 3, as much as possible. I have a new hobby, digital photography, and like to play around with my computer. I also read a lot.

I have been on the cadaver transplant list at Mass. General Hospital since 1981 and would jump at the opportunity for a transplant, but this is highly unlikely because of my high presensitization.

UPDATE — JANUARY, 2001

(I had the spinal fusion, which I consider only partly successful, as well as a second right hip replacement.)

In August 1999, I had spinal surgery that largely eliminated my back pain. In March of 2000, I had to have a second right hip replacement because the first prosthesis loosened. This time, the prosthesis is held in place by bone pieces from the bone bank and five loops of wire. It will probably take a couple of years to heal fully. Ten months after the surgery, I am still walking with a cane, but the hip is pain-free. I wonder if I'll ever play golf again.

My wife and I decided that we had been saving all our married lives for our old age, and that now was it. So we rented a newly built one-bedroom apartment in West Palm Beach, very close to where my wife's twin sister and her family live. We've been in Florida only a few weeks now, but are starting to feel relaxed and refreshed. The only drawback is that we

won't see our grandchildren—now numbering three—until mid-April when we return to Massachusetts.

We both feel pretty well, although my wife has a pacemaker and had a TIA last year. Because of improved dialysis technology, I feel I am better dialyzed than at any other time in my life.

UPDATE — JUNE, 2008

I apologize for not updating this for over seven years, but a lot has happened. I now have four beautiful grandchildren, and my wife and I now spend our winters in Florida, where we bought a condo in 2002. We are now “senior citizens.”

As for my health, I fear I have been ravaged (maybe too strong a word) by the many sequelae of long-term hemodialysis: bone disease, amyloidosis, muscle loss, heart valve stenosis, and, over the past two years, nephrogenic systemic fibrosis. Chronic back pain has made it difficult to walk, so I am much more sedentary than during my first 30 years on dialysis. I ride a mobility scooter in any situation that would otherwise require a lot of walking.

Nevertheless I feel well and am happy. Thrice weekly hemodialysis remains uneventful and I am taking an on-line advanced physics course at MIT. I am very involved in a kidney patient group (the Kidney Transplant/Dialysis Association) and continue with my digital photography. I do a small amount of computer-related consulting.

The changes I've seen in hemodialysis therapy have been evolutionary rather than revolutionary. Some of the improvements I've witnessed over the years include the A/V fistula, bicarbonate dialysate, hollow fibre dialyzers and volumetric control, EPOGEN[®], and kinetic modeling. It's now established that dialysis can keep CRF patients alive for many years, even decades in the case of patients who, as I was at the beginning, are younger and free of other systemic diseases.

The quality of medical care at most dialysis facilities—and I have been treated at many, including two cruise ship—is excellent. What improvements would I like to see? I would like to see dialysis facilities devote more resources to physical rehabilitation of patients. I'd also like to see more resources devoted to the well being of spouses, not just in the beginning stage of treatment but ongoing.

We'll talk again in a few years.