

My Twenty-Eight Years on Dialysis

By Richard L. Faber PhD

NOTES BY WEBMASTER [Curtis L. Atkin PhD](#) (September 19, 1999): As a researcher on Alport syndrome and an Alport - dialysis - transplant patient, I continually seek information that may benefit others afflicted with this disease. Rick Faber and I crossed paths on the Internet, and found some mutual experiences and interests. We have similar ages, are scientists, and suffered end-stage renal disease (ESRD) from Alport syndrome. He is Webmaster of [Kidney Transplant/Dialysis Association, Inc.](#), and also Editor of the "KT/DA Kidney Patient Handbook." Since the population of dialysis patients suffers at least 10% annual mortality, he is an extremely rare survivor of the 1968 cohort ("class of 1968") dialysis patients, making the few remaining survivors of my 1981 cohort look like pikers! I am thus pleased and honored to here republish the story of Dr. Faber's decades on dialysis.

NOTES BY AUTHOR [Richard L. Faber PhD](#): I wrote the original version of this article in 1970 while still on home dialysis. This was published in 1972 in the book "Hemodialysis: Principles and Practice," Academic Press, Inc. In 1973, I began in-center dialysis after an unsuccessful transplant. The Updates present more recent thoughts on my earlier views. This current (October 1, 1996) version of my story is reprinted and adapted with permission from the "KT/DA Kidney Patient Handbook," of which I am Editor, and which may be downloaded from the KT/DA website or thence purchased mail-order.

Three times a week, I spend six hours* 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 which houses a remarkable machine that substitutes for my own failing kidneys.

About three years ago (in 1967), I was entering the latter stages of uremia. I had resigned from my job (as a mathematics professor), 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 breathless.

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, play with my child -- everyday things that seemed forever lost to me. I even help out with housework occasionally (though I try not to make an obvious display of my talents in this area, especially in front of my wife). I enjoy exercise, and feel better for it. During summers, I play golf and ride a bicycle.

My diet is practically normal, and although eating had never been an especially great attraction for me in past years, I am now somewhat of a glutton who is becoming literally too big for his own breeches. 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.

Of course, there is still no perfect substitute for a real kidney, my own success notwithstanding, and I would be deluding the prospective patient if I did not delve into the difficulties and problems of adjustment inherent in home dialysis. If I extolled only the virtues of this therapy at the outset, it was because the virtues far outweigh the disadvantages in my own mind. Nevertheless, there are problems which cannot be overlooked, and which any prospective patient should be prepared to accept.

To begin with, 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. The loss of time was particularly annoying during the training period. Dialysis in the hospital kills the better part of a day. Treatment in the comfort and privacy of one's own home and at one's own convenience is much less of a hardship. Many patients feel tired or "washed out" after being dialyzed, and find it more pleasant to run the machine in the evening and then retire.

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. Side effects are as varied as the patients themselves. However, many (though not all, of course) of the minor discomforts patients experience are just physical manifestations of their mental anxiety. In my own case, worry over the death of another patient -- worry of which I was consciously unaware at the time -- caused me to have shortness of breath and chest pains for several nights in succession.

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. It is my contention that this problem of adapting counts as much as any physiological factors toward the variations found in the degree of success derived from chronic hemodialysis. In particular, a great deal of anxiety is attached to shunt care. This piece of plastic** is an admittedly vulnerable addition to one's anatomy. It is the patient's lifeline: a clearly visible symbol of the precariousness of his existence. Concern for its integrity is always lingering in his mind, and he must not partake in any exercise sufficiently violent to endanger it. It may last but a short time, or for years.

Problems can be kept to a minimum, however, through proper shunt care. A shunt never clots without some warning, and frequent, visual inspection of the top of the shunt loop will usually preclude any serious clotting. Daily washing of the shunt area minimizes the problem of infection. The patient has little control over possible leakage or skin erosion, but these are rare. In short, 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.

The attitude of the spouse plays a critical role also. If she (or he) shelters her/his mate from the minor chores and other activities of a normal life, he/she cannot possibly feel fully well. The wife who treats her patient-husband as a semi-invalid and who constantly laments the plight of her "poor sick" husband before friends and neighbors is giving the man a second handicap. My wife does not wait on me hand and foot, nor would I want her to. There is absolutely no reason for me not to do things for myself. Her attitude parallels my own: it is not a terrible thing that I must depend on this machine; but, rather, it is a wonderful thing that this machine makes me well.

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 three-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, or when I'm cleaning my shunt. She probably thinks that everybody's daddy has a machine like mine. We even make her feel a part of things by letting her "help" me with my dialysis supplies inventory.

She hands me the items one at a time, and I place them on shelves. It makes her feel useful and important, which, of course, she is.

Returning to work is a necessary part of good patient morale. A healthy attitude and a sense of purpose in life go hand in hand. There are few occupations too strenuous for a properly dialyzed patient, although those with sedentary duties or flexible schedules have an advantage. The dialysis patient needs something non-medical to worry about. Feeling sorry for himself 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. I have told almost no one at work about my condition, for I neither want nor need any special consideration from my employer. I enjoy my work and am very grateful that I can carry on with it.

Nothing offers more encouragement to the prospective dialysis patient than listening to one who is being successfully treated by this therapy. It helps him to realize that he is not about to submit himself to a mere maintenance measure that will just delay the inevitable, but, rather, that he will be receiving effective treatment that will keep him well and permit him to resume an essentially normal life. With this thought in mind, I have tried here to describe my feelings about home dialysis, with the viewpoint that mental attitude and adjustment are just as important for success as proper therapeutic technique. Life is a mental as well as a physical state. Home dialysis can truly be a gift of life, provided the patient can adjust his thinking and accept his plight. He really is not so badly off after all.

UPDATE -- May, 1971

It is now nearly three years since my first dialysis, and a little over one year since the preceding was written. I can state frankly that my attitudes toward this therapy have not changed significantly. My 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 one hundred percent 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

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

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

UPDATE -- June, 1988

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 text books. 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. 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

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 to 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 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.

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.

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 -- October, 1996

After my medical crisis in 1992, I decided to make my medical leave of absence permanent. I had completed 25 years of full-time teaching at Boston College, the last few of which were becoming difficult physically for me. It was time to call it quits.

My granddaughter Alexandra was born on May 25, 1994, and my grandson Brett, on June 20, 1996. These two kids have become the joy of my life and I love being with them. I keep busy with many things -- reading, walking, "surfing the net" with my computer and corresponding with friends and family via e-mail, taking day trips with Sue, and of course baby sitting.

I have come to realize that regular exercise is essential to a dialysis patient to maintain muscle mass, bone density, and stamina. Even just stretching exercises and regular walks can make a great difference in how well you do. I recommend it.

Good luck on your journey through life.

FOOTNOTES:

* With today's more efficient dialyzers, treatment times are now typically four to five hours, and even less with high flux dialysis.

** Nowadays, most patients have an arteriovenous fistula rather than an external shunt.