The afternoon is glorious, a typical Indian summer day with balmy southern breezes, and the trees with an abundance of color etched against a light blue sky. Before me is a pond’s tranquility, only occasionally interrupted by the honks of the remaining squadrons of ducks, mallards, and gulls. All that beauty, God’s gifts to us to savor before the onslaught of a cold and sometimes cruel New England winter.

In spite of all this loveliness, somewhere deep inside of me is a picture I can never quite erase, and perhaps do not really wish to. The scene drastically changes to a brightly colored, windowless room where row upon row of machines unceasingly toil at their life-giving task of refreshing blood for the next forty-eight hours.

It is so easy to describe the beauties of nature, so difficult to plunge ahead with the story of life artificially but gratefully prolonged, so I pause and look around me, as the birds peacefully glide by. But discipline, a key to survival, slowly ebbs back, as I do my best to describe a typical evening on a dialysis machine.

Arriving at the cold stainless steel front of the center, you pause with quickened heart beat, enter, nod a perfunctory “good evening” to the receptionist, and pass through a brightly colored corridor to the dialysis room. Walking to one of the four large bays, a technician and your life line, the kidney machine, await you. An elevated platform in the middle of the large, immaculate room serves as a control center and nurses’ observation post.

Greeting your friends in your bay, you settle into a bright blue chair for your four hour cycle, and hope you have lucked out with a good sticker (a technician skilled in inserting the large dialysis needles into your arm). After weight and blood pressure are noted on your chart, the needle insertion begins.

To digress a little, before you begin your dialysis treatments (days or weeks before), one of several surgical procedures is performed to ready your
arm. One of the favored techniques is called the *fistula*, which involves the connection of a vein and an artery to dilate the vein and provide easy access to and from the artificial kidney.

Back to the moment of needle insertion. The technician determines whether you want zylocaine, a local anesthetic, administered just below the skin, then the real sticking begins. If your fistula is reasonably good, your insertion usually goes quickly without much discomfort. Next, heparin is administered to prevent the blood from clotting the lines and dialyzer during the run. Then your blood is rapidly pumped through the tubing to the artificial kidney filter that will allow toxic and other waste substances, but not the large blood cells, to pass through it. This will purify the blood, a job normally done by the body’s kidneys.

If you have any of the following vein problems, the sticking may be unpleasant. Some patients have small, rolling, zig-zag or collapsing veins. to mention a few. Some have two or more of the above.

The rest of the evening will probably go fairly smoothly. If one has a pleasant neighbor, conversation turns to politics, news of the day, T.V. programs and, inevitably, some discussion about the technicians, doctors and your own particular medical situation. Unless you are experiencing serious problems, most chatter is not depressing nor are the medical problems emphasized.

If you have a smattering of curiosity, you’ll learn more about the miraculous machine that is your life extender, as well as how your anatomy reacts to it. If you have any sense of gratitude, you’ll thank God and your lucky stars that you are living in an era that allows you the privilege of dialysis.

Most people on the artificial kidney machine are remarkably cheerful, have great zest for life, and many accomplish a lot in between treatments. Some make very good use of their time on the machine as well. For example, teachers grade their pupils’ work and scientists read their technical journals. One cannot help but be inspired by the courage of these and other patients.
At the center, you meet a number of people who are on dialysis because of transplant rejection. Organ transplantation is successful for many. The lucky ones are leading completely normal lives. Some, unfortunately, have gone through that critical medical procedure two or three times. One young lady, now 20 years old, has had three unsuccessful transplants and is always bright and cheerful, even though the last time I saw her, she was on crutches. Another young man, a senior at M.I.T., also had a transplant that rejected. After much trauma and ill health, he is struggling to maintain his college grades. The main thing is that those young people, and others, continue undaunted and are making it.

The gamut of patients is varied in health, occupations, and avocations. As hinted at before, many on the early evening shifts are gainfully employed. Several are medical doctors; no one is shown any favoritism as far as kidney disease is concerned.

One special friend of this writer is a fine, bright gentleman in his late sixties. Although officially “retired,” he would outdo many a younger person. He swims vigorously three times a week, drives twenty-five miles each way to dialysis, gardens, takes courses, and in general enjoys life and his family.

As the evening progresses, blood pressures are monitored and hematocrits, a measure of red cells in the blood, are taken. These are routine ministrations. However, some patients must have frequent transfusions because their blood-producing tissue, the bone marrow, does not function adequately, hence red blood cell production is insufficient for the body’s needs when a patient’s kidneys are removed or become inoperative.∗

Another problem, commonly referred to as “crashing,” may rarely occur. This is a polite term for a rather nasty experience, namely losing or nearly losing consciousness, vomiting, etc. This condition usually responds to the administration of saline solution to the ill patient.

Finally, the four hours are over. The needles and tubing connecting the patient to the dialyzer are removed. After a period of time to clot the blood at the needle sites, bandaids are placed on the punctures and the

* With the advent of EPOGEN® (or EPO, see Chapter 20), the need for blood transfusions in dialysis patients has been greatly reduced.
patient is weighed and charted. Soon he is on his way home, only to repeat this all again two or three days later.

This article would not be complete without recognition and special thanks to the doctors, nurses, and technicians who keep the center running day in and day out. Although dialysis for the majority of patients is at a center devoted specifically to dialysis, many acutely ill patients are treated in hospitals with much care, love and dignity; and many others dialyze at home.

Finally, besides the patient’s own will to live and determination to abide by the rules of diet and medications, is the love and support the patient’s family and friends give. Without this, even the most determined patient would have difficulty struggling against a difficult disease in a sometimes uncaring world. With it, life can be beautiful, if not idyllic.
6b—Twenty-five Years on Dialysis
Richard L. Faber, Ph.D.

(Editor's Note: The following article, reprinted from Hemodialysis: Principles and Practice, Academic Press, Inc., New York, 1972, was written in 1970 when I was still on home dialysis. In 1973, I began center dialysis after an unsuccessful transplant. The Updates following this article present more recent thoughts on my earlier views.)

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 3 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

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

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* Nowadays, most patients have an arterio-venous fistula rather than an external shunt. (See Chapter 9 for a discussion of circulatory access methods.)
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, 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 nonmedical 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 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, 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 — J U N E, 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.

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.