Chapter 7

A PERSON, NOT A PATIENT:
A Prescription for Learning to Live a Normal Life on Dialysis

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A few months ago, I had made a promise that I would write an article concerning dialysis. I had delayed in fulfilling this promise for quite some time now. The reason for the delay was simple: writing an article meant disclosing a part of my life which sets me apart from the norm. In the past ten years while on dialysis, I've managed to carve out a normal existence. I am recently married, well-educated, and have an interesting career. Disclosing my medical condition could very well disrupt my normal existence.

Experiences have taught me that "healthy" people pass through four phases of adjustment when first learning of my medical condition. The phases are: shock, curiosity, adulation, and finally, the phase in which I am now, treating me as if I had no medical condition. In *shock*, people can't believe I'm "sick." Instead of engaging in a conversation based on free information, such as, "How is the weather," the conversation begins with dialysis/patient jargon such as, "How do you feel?" or a very popular tune, "I know a person who has been on dialysis for five years." The message I receive from this is that I am unique. Not unique in an exemplary manner, but unique in that I am perceived as "sick." The perception that you are "sick" does not contribute to your self-esteem.

The second phase is *curiosity*. In curiosity, people are interested in the specifics of your condition. They want to know how many times per week you need dialysis or if the treatment hurts. Sensitive people refrain from asking too personal questions. Some people, however, need to know every detail of every operation.

After satisfying their curiosity, the next phase begins, *adulation*. In adulation, you are perceived as courageous and heroic in handling your personal problems. This becomes particularly true when people begin comparing their problems with yours. In many instances, this adulation is mixed with a high degree of paternalism. This paternalism reveals itself when relatives or friends lower their expectations of you. For example, I

have a friend who happens to have a friend on dialysis. My friend feels this person is doing well, well enough in fact "to eat pizza, drink beer, and dance." When asked if this person had any intention of returning to her clerical job, she felt that was an unfair expectation considering her condition. The adulation is comforting to hear while the paternalism is easy to ignore. The combination though act as a perfect catalyst for self-pity.

The last phase means being treated as if you had no medical conditions. It means being accepted for what you are and do. It means having a job or career and outside interests. It means living a full life, regardless of dialysis. It also means learning the physiological parameters of dialysis and realizing that you are still worthwhile to yourself and others and that you can be loved. The illness and the events surrounding the illness make this a very difficult adjustment. In fact most "healthy people," who have the same needs to be loved and the same needs to feel worthwhile vary remarkably in their ability to fulfill them.

For a person on dialysis, it is much more difficult to have these needs met. Physiologically, one of your most basic requirements for life, the need for the removal of waste, is now being performed by an artificial device, which operates far less successfully than your original healthy kidneys. Psychologically, because of a whole series of internal reasons and external events, you may very well have stigmatized yourself and have been stigmatized as a dialysis "patient." The word patient connotes sickness. The word patient perpetuates the assumption that a person on dialysis is non-functioning and dependent. If the people around you treat you like a patient, it is pretty normal to start viewing yourself as a patient. If you view yourself as a patient, then the expectation that you should meet your needs while on dialysis is severely diminished. How can a person who has been stigmatized as being "sick" and non-functioning and dependent feel worthwhile or have a positive self-image?

When you begin dialysis there are many adjustments to make. For most people it may well be the first time you've needed surgery. You must learn to live with a shunt and tolerate multiple punctures of either your arm or leg. Your diet and drinking habits are drastically changed. You lose weight and your muscles may atrophy. You may look pale and jaundiced. In

the hospital you're bombarded with information about blood pressure, fluid overload, calcium, potassium, medications, diet, transplant, cadaver list, TMP, Medicare, and blood flow. It is an endless stream of information presented to you when you're feeling the worse you've felt in your life. To complicate matters, your first few dialyses are uncomfortable. Your access sights ache and you itch. You might cramp and shock. Dialysis appears as an endless array of problems. As a patient in the hospital you live according to the institutional routine. Dialysis at seven-thirty, back to your room at one, a snack at three, dinner by five, family at six and sleeping pills by nine. The procedures in the hospital and your first few uncomfortable dialyses have established a pattern and attitude of dependence.

This attitude of total dependence is transferred with you when you are transferred for dialysis at a free-standing facility. At the free-standing facility, you arrive early and sit dutifully in the waiting room with the other somber faces. At precisely the scheduled time you're allowed to enter the unit. Once you have hung up your coat and greet your therapist, you're escorted to the scale for the ritual weigh-in. As you stand on the scale you're reminded by the sign that you must have your weight verified by a staff person. At one time you might have been responsible enough to raise a family, but now you're not responsible enough to weigh yourself.

Once you have had your weight verified, the staff person escorts you back to the chair, takes your pressure, cleans your arm, computes your weight loss, brings you a blanket, adjusts your chair, and gives you a pillow. In a most insidious and subtle way, the institutional procedures of the free-standing facility and the behavior of the staff reinforce the attitude that you're a patient.

There may be further problems which compound your condition. You may have enormous medical bills and in most instances have not worked in the past few months. In fact you might even question your capability to work. You sense there is a change in the relationships with your family members, and you might question your sexuality. The only hope appears to be a transplant. Experience has taught me that people in this predicament are analogous to the drowning man grabbing a piece of straw hoping it was a log. However, in my opinion, there is a sequence of events which, upon

completion, will lead to a better self-image, an improved quality of life, and an objective approach for selecting your modality of treatment.

The first step in adjusting to dialysis is learning the clinical aspects of kidney failure and dialysis. It is imperative that every person on dialysis know the diet, understand blood chemistries and medications, learn the process of dialysis, and how to deal with the side effects of the illness. If a person can learn the clinical aspects of the disease and the treatment, and can apply this knowledge on a daily basis, that person will physically feel better. Once you're following your diet and watching your fluids, your treatments will be less traumatic. In some instances, the itching will be less pronounced and the number of cramps may become less frequent.

In terms of the effects of the treatment, it means understanding a simple concept like your blood pressure. For example, if your pressure is low, this doesn't mean the entire day must be spent on your back with your feet in the air. It does however mean rising slowly and drinking extra fluid. A low hematocrit doesn't mean huffing and puffing when you take in the groceries, but merely means taking in four light bags instead of two heavy ones.

Third, learning the process of dialysis enables a person to control the machine that keeps him or her alive. Only the person on dialysis really understands his or her dry weight and stamina. If you can understand dialysis and its effects, you will be better able to relate to the medical staff. A person on dialysis who has gained the confidence of the medical staff will be given some degree of latitude in his or her treatment. For example, if your medical record indicates your dry weight is 63 kilos and you feel your dry weight is 65 kilos, chances are that you may not be dialyzed as hard. Imagine every time you dialyzed you ended up weighing two kilos below your dry weight. You certainly wouldn't feel well after each treatment.

Finally, controlling your dialysis means controlling your health. Controlling your health means being less dependent on the people around you and the medical staff. Being in control and acting independently is the first step toward a better self-image.

Once you're feeling better and have an understanding of the circumstances of your medical condition, start thinking about long-term and short-term objectives. Long-term objectives involve your career or education. Short-term goals pertain to daily or weekly activities. An attitude I have found prevalent in many people is that dialysis is only a phase of their lives and they will lie back and wait for the transplant. Once they have had the transplant, they will resume all their previous activities prior to dialysis. This attitude is naive. Statistically speaking, transplants are merely a reprieve from dialysis. Many transplants fail over time. Lying back waiting for the "cure" is a waste of time which could be used in a productive manner.

A productive use of this time while on dialysis could be continuing your education or finding a new career. A long-term goal of a business executive on dialysis might be resuming a full-time career, while for a coal miner it would mean a career change. Choosing long-term goals should involve professional assistance from a social worker or a rehabilitation counselor. A short-term goal of increasing your outside activities could be either joining a bowling league or making your own snack instead of relying on your family.

These goals should be realistic and obtainable. When you're feeling badly about yourself, you don't need to be reminded that you're a failure by establishing goals beyond your capabilities or means to achieve them. Nothing succeeds like success. Once you've accomplished an objective, establish another. If you graduate from high school, go on to college. If you walk four blocks a day for exercise, increase your walk by a half block every two days. Establishing goals and achieving them is the second step which will enable you to learn to live a normal life while on dialysis.

The last step involves choosing the treatment which best coincides with your long-range objective. People on dialysis have three alternative methods of treatment of end-stage renal failure: home dialysis, dialysis in a hospital or free-standing facility, or a kidney transplant. Each of these options has its own peculiar positive attributes and negative consequences. I suggest that each person discuss the consequences of each form of treatment with his or her physician, particularly the negative side effects of

a kidney transplant. Once you have learned the consequences of each method of treatment and have begun to achieve your long-range objectives while on dialysis, choose the method of treatment which best fits in with your long-range objectives.

For myself, this means continuing dialysis at a free-standing facility, continuing my career as a health planner, and eventually trying for a third transplant. I will not, however, put myself on the cadaver list until I have made certain arrangements. The first is to educate my co-workers and supervisors of the time I will need to recover from the transplant. I certainly would not want to have a transplant and lose my job because of excessive absenteeism due to the surgery. Secondly, I want to set aside a sum of money which will enable me to take a six month leave of absence after the transplant, to be used either for recuperation if there are medical complications, or a vacation. After ten years of dialysis, I feel I have earned at least six months of travel.

In essence, I am advising people that if they choose a transplant, they should be in a position, whether the transplant fails or succeeds, to continue (after a brief recovery) with their career objectives. Do not place yourself in the position where your entire future depends on a successful transplant. Desperation is a fool's reason for a transplant.

By no means do I wish to suggest that every patient who reads this chapter is capable of living a normal life while on dialysis. There may be medical problems beyond your control which prevent your total rehabilitation. All I ask is that you evaluate your life on dialysis and strive to be more independent.