

# How Does a Home Dialysis Patient and His/Her Family Feel About Home Dialysis?

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We, the staff involved in the training of patients for home dialysis take certain things for granted. We often hear patients talk about their fear and often their outlook on life is unrealistic, at least in our opinion. When you are dealing with patients on dialysis you are asked questions such as; What are my chances of survival? What do I have to look forward to? What quality of life will I live?, etc.

With this in mind I have asked the husband of one of our home patients to write an article to make us aware of some of the emotional, as well as other problems that they have to cope with. As you will see, it was a slow process to rehabilitate the patient. Why, exactly, this woman has such a low energy level, we do not understand.

This married couple has two sons, age 14 and 9. Joe told me that the whole family is involved in this. Beverly has been on dialysis for over two years. Joe will tell you his story and he calls it: "Some Observations about Home Dialysis."

## SOME OBSERVATIONS ABOUT HOME DIALYSIS

I suppose we were shocked to find that my wife would have to have dialysis in order to sustain her life. The announcement had come down on us like a landslide of rocks. I suppose we were in shock for several months. We had heard so many things about dialysis, but it seems that most of what we had heard was not completely true. How do you pay for something that is so expensive? What is it that dialysis does? How do you handle it? Why us? These and many more questions raced through our minds as we struggled to try to come to terms with this new enemy that had reared its ugly head. First, an emergency dialysis, then a shunt was placed in the patient's arm. Within a week it had clotted and had become ineffective. A second shunt was placed. Within two days it had clotted and become ineffective. Finally, an A-V fistula was placed in the other arm and it was successful. During this time, the technicians and doctors continued to administer dialysis in the hospital to maintain the patient. Even though things were going well, it seemed to us as the family and the patient that each day we would open a new dark door . . . not knowing what to expect, not knowing what we might do if another crisis should arise. Oh, how we wished that someone would just explain to us what each new crisis meant and how we could best deal with it. Perhaps through the repetition of being close to dialysis and working with many many patients, the personnel at the hospital and at the training center had begun to treat as routine something that we as patient and family feel is very vital.

After they had stabilized Beverly's condition, the training center began to train her in administering dialysis. They also began to train me as the spouse so we could administer dialysis in the home. While Beverly was in the training center, we also remodeled a room in our home to accommodate the dialysis machine, and we also built a storage room on the back of our garage to store the supplies. As anyone who has been a patient on dialysis or who has been close to a patient on dialysis knows, the pressure of this time in the program can be very great. There are the pressures of

traveling to the hospital and staying there all day for three or more days each week, and of the spouse trying to work a full day for his employer and still be able to help in the training, and of arranging affairs at home, remodeling, caring for children and on top of all of this, the worries of paying all of these astronomical expenses. Those who have experienced these pressures will understand; those who have not can only speculate. Fortunately, I had an employer who seemed to be very understanding and allowed me to have a flexible work schedule so I could meet the needs of the dialysis program. As for the costs of dialysis, we were also very fortunate that our employer provided a very generous insurance program.

It seemed that things were pretty much touch-and-go for nearly all of the first year. Even after Beverly had been on dialysis for a year, she would need to rest four or five hours every day during the day in order to function even partially in helping the family meet the daily needs of living. On occasion during the first summer, almost a year after going on the program, she would walk from the house out to the flower garden to work in it, but by the time she would get to the flower garden she would be so tired that she would not be able to work and would have to return to the bedroom and lie down for the remainder of the day. It was very discouraging to her and to the family. During the second winter we realized much more success in dealing with dialysis. By the second summer in the dialysis program, the boys and I planted a special flower garden for Beverly right next to the back door so she wouldn't have to go so far. This arrangement, together with Beverly's increased energy level, helped improve our life style. (The flower garden was very successful.)

Our dialysis program now seems to have stabilized and we have, by trial and error, found the systems that work best for us. We have dialyzed on different days of the week, and we have dialyzed different times of the day. We now feel that we have developed an acceptable life style and pattern of living that includes dialysis. We are finding that a certain schedule does work better for us and we also feel that each patient and family must find their own life style around dialysis because what will work well for one family certainly will not work for another.

One of the unusual things that we have observed during dialysis is that the process seems to affect Beverly's thinking. During the first winter, we found that she would even have difficulty following the plot of a television show while undergoing dialysis. Since then we have noticed, occasionally, that she will even act and talk irrationally and almost deliriously while on dialysis. It would almost seem as if there is some chemical disruption of the thinking process. We have been acquainted with experiments with animals where the neural processes have been altered by chemical stimulation, and it is not too difficult to extrapolate from that to the rather unusual behavior of the patient while on dialysis.

As we have grappled with this once mysterious monster of dialysis in the home, we have realized that as a family, with our own unique life style, we have needed a way where we could work well together. We soon realized that nothing is as boring as sitting for six, seven, or eight hours, three evenings a week, and doing nothing but watching television. Just sitting is even worse. We decided that we needed to make this a productive time. As a result of this, we began looking for hobbies that we could engage in while tied down by dialysis. We have tried a number of things, and we now have one project going that is beginning to produce for us. We are able to do these things while on dialysis. We have part of the hobby shop in the garage, and we have arranged an alarm bell signal system so Beverly can signal when she needs assistance. Beverly is also able to perform some of the work required by the hobby. We are making gift items. We feel that we cannot just sit there and be dialyzed. We feel that we must attack when we are oppressed.

We feel that for our life style, we must also have better mobility. We need to feel that we can leave home any time we want without the major complications of

arranging for hospital dialysis at the cities we visit, or without having to make appointments or reservations for specialized equipment and actually, without any real forethought. We need to go and do the things that other families do. We have looked at trailer houses. We have looked at campers, vans, Volkswagon vans, Dodge vans, mini mobile homes. You name it and we have looked at it with the objective of giving our family the mobility that we feel we must have. On a very minimal basis we feel that a Volkswagon van combined with a very compact and extremely mobile dialysis machine could provide the mobility that a family needs. However, because of the limited energy of Beverly and the need for rest and relaxation when we go, our family has settled upon one concept, and that is a mini motor home. It is compact and yet is large enough to give us the things that we feel that we must have. This mobility is now our major objective.

If we are to identify areas of concern where dialysis could be improved for us as a patient and family, we would say:

1. Great care should be exercised in establishing more complete communication between the patient and the family on the one side, and the dialysis instructors on the other.
2. We would like to have a machine that is very compact and mobile, so we can travel and be free to move about as other families.
3. We would like a machine that would dialyze in less time, and that could be easily set up and disassembled after dialysis.

We as a patient and family deeply appreciate the present capabilities of the home dialysis program. At the same time, we look forward with great anticipation to the time when we can enjoy a life style not too different from most other families.