

SPOUSE: A WIFE'S VIEW OF DIALYSIS

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While we, as spouses, are not the patients, we live day-to-day with the disease and the successes and problems that are associated with living with end stage renal disease. Whether the method of treatment is chronic hemodialysis, peritoneal dialysis, CAPD or transplantation, loving and living with a patient who is faced with extending his/her life with this treatment does not let us escape some of the turmoil patients feel. Though we are not the “*sick*” member of the family, surely we face the problems with them, and our lives are affected by their varying degree of “*wellness*.”

First, let me review some of the history which I have found during the years can be so similar for all families. My husband, then 27 years old, hadn't been feeling well, so he saw a doctor. We knew he had a kidney problem, but never realized its potential seriousness. We were only kids then. I was 26, we had a baby three months old. We didn't expect to hear that he had a major health problem. In retrospect, I think we just expected he would get some medication and be fine. As I remember, we initially were told not to expect anything radical to happen for five years, which seems a long time when you are in your 20's and just starting out with a young family, a new job, and a new house, all in a new state and no family around. But, like many of you, we soon found out that kidney disease progresses slowly until the kidneys reach about 10% of their kidney function, which in most cases is rather late in life. That is when the patient starts to get the familiar symptoms, and it becomes apparent that treatment is necessary.

Over 26 years have passed since we faced that problem in 1967, and shortly we will have celebrated the completion of his 25th year on dialysis—that's three treatments a week, 52 weeks a year or 3,900 treatments ago. Twenty-six years ago people were dying for lack of kidney machines, transplantation was only a one-shot affair, and chronic dialysis was a medical experiment. Our hope was that transplantation would be the ultimate cure.

For the first 5 years of his treatment, we were on home dialysis. Since then, he has dialyzed at a kidney center. I have no recommendation regarding home dialysis, except to say that it is probably best for the patient—given the freedom of treatment. However, the whole family is on dialysis (time, schedule, routine, and responsibility for the spouse who helps with the dialysis treatments). Today many families are able to afford nurses or technicians, either as a permanent or temporary assistant, to take the burden of responsibility and some vacation or free time from the family caregiver. While the patient has to adhere to a rigid schedule when treated outside the home, the family, and in this case the spouse, has more freedom and no responsibility regarding treatment. Some of us have used this “free” time to extend our education, get a job, drive our kids to endless after-school activities (gymnastics, sports, etc.). If you talk to people regarding their feelings about various methods of treatment, they will usually favor their current mode of treatment. Although everybody wishes for a successful transplant.

My husband had his ups and downs for the first year. He was one of the first patients to receive the arterio-venous fistula, and I was one of the first spouses to learn to put the needles in his arm so that he could receive dialysis treatments. This was quite an improvement for the patient over the external shunt (there was no longer worry about external tubes, infection, or daily care regarding the access site). I remember those days well. I never looked forward to dialysis treatments and was relieved when the treatment was started. I must say here that all the spouses I have known that had to master the technique of placing needles were able to accomplish this task.

When children of a patient are young, they may think everybody’s daddy is on dialysis, that dialysis is fun, and it is no big deal. As they get older, they too must learn to live with the disease. We thought our young daughter, now 26, knew and understood about kidney disease, dialysis, and kidney transplants. She did, but it took us a long time to realize that her level of understanding was much different from ours. She once told me that when she heard her daddy had a transplant, she thought a miniature kidney machine had been placed inside his stomach—even though we had

explained in detail why daddy was away and what was being done; she was five years old at the time. (The transplant was unsuccessful.)

As a family, we took one day at a time—cherishing the times we spent together. It was nice when the baby got up after dialysis and we played with her for a while. We even enjoyed it when, on home dialysis, she went to check on daddy. We made her a part of the treatment. She assisted him in fixing the television, bringing him a snack, or anything she could or wanted to do. Mostly, she kept him company. Sometimes she even pretended she too was on dialysis. I remember sometimes I would place a piece of plastic tubing on her arm so she could sit like daddy.

We always made the family time special—doing things with our daughter and sometimes with her cousins when dialysis didn't interfere. Our Saturdays were usually spent going out for Chinese food (which we all love) and then to the movies. Just watching television together was something we liked to do. Sharing is the operative word here.

The first three years were especially hard for me. Our daughter required care as all toddlers do, and the home treatments consumed eight hours (including setting up the machine and cleaning afterward). Gradually, as time went on, my husband came home earlier from work to set up the machine. After the treatment he helped clean up. He also decided to learn to become more self-sufficient on the machine and started putting in his own needles, which he does to this day. He initiates and monitors his own dialysis treatment at the kidney center.

If I had to give advice to any family facing dialysis treatments the following would be on my list:

- Let the patient treat himself whenever possible.
- Let the patient make sure that he/she has his/her medications, that it is the patient's responsibility to take them and to have them on his person.
- Don't become the patient's nurse or doctor.
- Understand what dialysis is, how it works, and how it affects the patient and make sure that the patient has the same knowledge. Usually it turns out that you have complementary knowledge. As the years go on you should know equally the when, how and why about dialysis and transplantation so that you can make future

- decisions which may become necessary with knowledge and understanding. Of course, in the final analysis, the patient must make all decisions in his/her care. Usually, however, families become involved in major decision discussions.
- Understand that the patient has limitations and don't make him/her feel guilty because those limitations might interfere with "normal living."
 - Share your fears and apprehensions with your spouse, the patient, whenever possible. He/she must know that you have anxieties too.
 - He/she is not your "poor sick" husband, wife or significant other. Patients have handicaps, but like most people with medical problems they can live a normal life with few limitations—if they make up their minds to do so.
 - Be prepared for changes of treatment—starting dialysis, going on the list for transplantation, changing methods of treatment. Patient, as well as spouse, should be informed as to what to expect. Hope for the best results, but be prepared for the unexpected.
 - Moral support of the patient is extremely important.
 - It is hard to say try not to worry about what might be. That is the hardest thing to do (not worry). Enjoy the present. Spending ten years worrying about whether my husband was going to live or die affected me, not him. Since I learned I have no control over what happens to him, I am much more free of fear. I still have anxieties, but I don't wake up in the middle of the night to check to see if he is breathing.
 - The patient must make the final decision (after discussion with his/her spouse) about the type of treatment he/she selects.

In the past 26 years, there have been a lot of changes in the treatment of patients with end stage renal disease. Treatments in 1968 were six hours—now they typically last three to four hours, and there are more treatment options (patients can have more than one transplant, and there are several different types of dialysis treatment). There are new drugs being used to prevent rejection and transplants are lasting longer. Both dialysis and transplant patients have a better quality of life as each year passes. Many patients work full time jobs (including my husband); others, who are unable to work, still fill their hours with non-traditional work like volunteering their time and holding down the fort at home. Role reversal sometimes becomes the necessity rather than the option we find in today's society.

Today, there is the added burden and anxieties connected with employment. Our economy is in a recession and many two income families have now become families with one income. or worse yet no income. Money is short, insurance costs are increasing, and there may never seem to be enough money to cover expenses. Of course, we are not unlike the general population in the United States, except that most people do not have the added problem of end stage kidney treatment.

In 1967 I didn't know whether my husband would live six months and I would become a young widow. Now after 26 years, we have seen many friends and relatives die (who were healthy and did not have any illness in 1967). Sometimes I think they never realized how important the little things in life were that we all take for granted. We realized early in our marriage to live each day and appreciate life.

My husband has been on the list for a second kidney transplant for several years. Having gone through one unsuccessful transplant 20 years ago, I know something about the possible problems. Knowing successful transplant patients whose kidneys have lasted more than 25 years has also helped us look with optimism to the future.

I would be misleading you if I said marriage as the wife of a kidney patient is all fun and games—it is not. In 26 years we have had our ups and downs. I have found out that sharing experiences and feelings with other spouses of kidney patients is very beneficial. That is one reason why I have shared our experiences with you in this Handbook, and why I have been active in the Kidney Transplant/Dialysis Association. Seeing the look on the face of a patient or spouse who is new to treatment (or an experienced patient/spouse who never considered this treatment long term) when they hear my husband has been on dialysis for 25 years is a boost for both of us. Twenty-six years ago we looked to life in the short term (months, years), now we know that patients can go on indefinitely (for decades) to live near normal lives—to have children, raise them, and see them graduate from high school and college and marry, and to see their grandchildren.

Much as we wish to deny it, as the years have gone by and I have come to know many patient families, I realize that chronic illness in a family

affects children. Supermom (or Superdad) is a definition of the 80's, but we as spouses of patients and patients themselves defined that word long ago. It took the businesswomen of the 80's to give it a title. It is my hope that as children grow up, they will take comfort in the fact that their parents adjusted and survived the trials and tribulations of their life with courage and dignity. Seeing that, I hope will give our children the courage to live their lives with the same fortitude as their parents. If children learn by example, they too shall overcome.

In closing, I wish to dedicate this chapter to the many spouses and patients that I have known during the past 26 years. We have developed a bond that will last forever. We have lost many friends during these 26 years, but they were the very best of people. They were the kind of friends most people never meet. We shared experiences, feelings, fears, and joys with each other with pain and grief mixed in. But we learned to love and care for each other in a way most of the population never learns. Through the KT/DA, we have met people we never would have met. We learned we are all the same (whether patient or spouse)—helping, sharing, living; we are survivors helping others survive. And we are better people for the experience even though we would all agree we wish we could have achieved this outcome without the problems associated with a chronic illness.

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I have reviewed this chapter, making some of the changes to dates and references to treatments. Dialysis is very common now. Many people I meet often know of someone on dialysis or a patient with a successful transplant. My husband and I went through the usual years of career goals. Now, both in our early 50's, we have come to the realization that we want to "*stop and smell the roses.*" We both limited our work this summer and played a lot of golf (yes, both of us walking 18 holes of golf). It is something we both enjoy and can do together.

Our daughter is now engaged and we are planning a wedding in May next year. We have been married over 28 years, which even for a healthy couple is unusual in this day and age. Our lives are not as perfect as we had hoped 28 years ago, nor did we expect that someone could live a nearly

normal life on dialysis for a quarter of a century. My husband remains active in KT/DA. I have limited my activities in KT/DA just because I need some time for me.

June, 1993

Well, another year has past since my last update. I am glad to say that our daughter, Lynn, was married on May 15, 1993, and I am still basking in the glow of the evening and the events of the year filled with planning the wedding and becoming part of another family. We have a wonderful relationship with my son-in-law and his family. Seeing her settled and married is wonderful for both my husband and I because she was so young (three months old) when my husband initially took sick. The newlyweds are planning on having a family, and we are looking forward to becoming grandparents within a few years.

On the down side, my husband took very sick (for the first time in 26 years) and almost died twice at the end of 1992. He was hospitalized for six weeks. It was a very difficult time for all of us. We have been fortunate that he had no major problems during these 26 years. Certainly, sickness in one's family is a test of love and courage, but love is not always enough to sustain a marriage, as evidenced by the fact that divorce is common among families living with all kinds of chronic diseases. Facing those catastrophic times and not knowing sometimes from day to day whether he would survive, reminded me of how much I still loved him. Seeing our daughter, not as our child, but as a women (26 years old) face this time with courage and support for both of us, gave us strength as we watched husband and father gain his strength back and become the person we knew. He is still not back to his former strength of playing and walking 18 holes of golf, but we plan to work on it. We believe his physical activities during the summer of 1992 made him strong enough to survive his health crisis in November and December 1992. We face new challenges in the future, but then doesn't everybody.

As I reviewed this article, I realized that life has come full circle. We are now our "parents" and our daughter's generation is the future. As we look to a future with health care for all, I hope that illnesses will be caught

before they become serious. I hope that beside helping the patient, that the new health care system proposed by President Clinton, will help families caught in the hassles of catastrophic illness.

Most of all, I hope that sharing some portion of our lives during the past 26 years will prove to you that kidney failure is not a death sentence, but an adjustment to a different way of life.

We'll "talk" again the next time this handbook is revised.