

# The Spouse of the Dialysis Patient: *For Better or For Worse*

by Ramiro Valdez, Ph.D.

"My wife left me because I'm on dialysis," Jimmy was about to cry as we sat in my small clinic office. In the three years since his kidney failure, we had built a very good rapport.

"She didn't leave you because of dialysis," I proceeded cautiously. "She left you because you stopped listening to her like you did before you got sick; you stopped asking her to the movies. And mostly, because you didn't make time to be a husband to her. You were too busy being a sick kidney." As much as this shocked him, he thought over what I had just said.

"You damn social worker!" he chuckled. "I never could pull anything on you!"

At session's end, I thought about the number of spouses of renal patients who suffer in silence with no one—sometimes not even their spouses—to turn to.

## **Kidney Failure Seldom Strikes in Isolation**

Jan Zapata, the wife of Manuel Zapata, a transplant patient and former board member of the American Association of Kidney Patients, once told me, "In all the years Manuel was on dialysis and the many times I went with him to the clinic, doctor's office, hospital and so on, no one ever asked me how I was coping with dialysis." To her credit, she coped well, in spite of the truth in what she said.

Regrettably, Jan's case is not unusual. The kidney patient's spouse has to make many adjustments, just like the patient. Dietary restrictions, role reversals and financial pressures are just some of the challenges that affect the spouse as deeply as the patient. While patients may complain about frequent trips to the clinic, it is often the spouse who drives the patient to and from, then waits alone in the lobby while the patient is attended. Yet spouses are seldom helped with the adjustments required by renal failure.

## **The Stress of Renal Failure on Marriage**

Many patients are unable to work. Previously working patients become "stay at home spouses." Men, who often define their value and identity as the "breadwinner," are hit especially hard. Yet, women as well find themselves enduring not just a role reversal, but performing the roles of breadwinner and homemaker, since many men will not help with housework.

Financial problems, the plague of renal patients, often affects spouses harder than patients. They often become the sole breadwinner and frequently feel guilty about their resentment and anger. After all, they tell themselves, how can they expect someone so sick to help with the money problems or the laundry? They seldom have anyone to tell their feelings to without being scolded or judged.

Virtually dozens of kidney patients have told me they no longer sleep with their spouses. It's not just sexual problems, but the restless legs, the insom-

nia, the phosphorous itching and so on, that make it difficult for the spouse to sleep. So they end up in separate beds or separate rooms. This is just as difficult on the spouse as it is on the patient.

### **Balancing Marital Needs in Kidney Failure**

The obvious solution to the dilemma is for the patient to continue to fill the role of supportive spouse, even in the face of kidney failure. This is no easy task, but to neglect it is harder on the marriage. Marriage is not an easy endeavor, for healthy people as well as everyone else. Sometimes chronic illness makes us forget this. Following are some pointers from patients who have been able to maintain strong relationships.

**1) Focus on the friendship in the marriage.** No matter how sick a person, it takes little effort to ask the spouse "How was your day?" or "How are you coping with this kidney stuff?" Some spouses will respond cautiously, not wanting to hurt the patient's feelings, but giving the spouse permission to be hurt and angry about kidney failure can help focus the emotions and make the adjustment easier. A strong friendship is an excellent predictor of success in marriage, and taking some time to listen to each other is the mark of any solid friendship.

**2) Talk about things besides your illness.** Some patients talk about their illness daily. This causes the couple to become more and more alienated, which could lead to the sick partner feeling sicker and the healthy one feeling guilty. It's like a person in a nursing home who gripes about not

feeling well and that no one comes to see her. The result is that people want to stop coming to see her, thus causing her to feel worse. Talk about your illness often with your healthcare team and occasionally with your spouse.

### **3) Continue to be a fun person.**

People want to be around people who are fun. Chronically ill people can still be fun. Some patients are too sick or weak for dinner and a dance, but they can sit through a movie or a visit with friends. It is especially meaningful if they can hold hands during the movie or visit. There are numerous things a couple can do together which require little stamina and money if they think creatively. The extra effort will work wonders for the healthy spouse—and the marriage.

**4) Ask staff to talk to the spouse also.** Simply asking the doctor or social worker to talk to the spouse will show the spouse that he or she is important too. The staff may not know there is a need for this until the patient points it out. Including spouses in care plan meetings and doctor rounds can let the staff know that kidney failure has affected two people.

**5) Help the spouse see dialysis as a positive, just as you do.** Some spouses would rather not get involved with the clinic. They should not be forced. But even spouses who will not enter the clinic or hospital are enlightened by your telling them good things about the clinic. A holiday party, a new doctor, a patient who got a transplant or a new job, even a good book exchanged among patients can be shared as a positive experience at the clinic. This helps them see that clinics

and doctor's offices are not all gloom and doom, but can be positive and even fun at times.

### **Kidney Failure as an Opportunity for Growth**

The old saying "This will either make us or break us" can certainly apply to kidney failure. There are many terrible things about a chronic illness and no one can make it fun. But it is possible to turn the illness into an opportunity for growth. Taking the time to ask the spouse how he or she is coping and making the time to listen is one way to enrich the marriage, and a stronger marriage could mean a healthier patient. Maybe focusing once a week on the needs of the other person can make the spouse want to stay around for those other times when the focus must be on the illness. Making an effort to be a fun person, even in the face of adversity, will give the spouse a few laughs here and there and remind him or her of why they got married in the first place. And kidney failure can become yet another way to strengthen a marriage.

Jan Zapata, and others like her, was helped by her husband when no one else would. Perhaps this is one of the reasons her husband became a great leader among renal patients. Perhaps the old saying "Behind every successful man there is a woman" should be expanded to "Behind every well-adjusted dialysis patient there is a well-adjusted spouse." And it happens when the patient is able to focus more on the marriage than the illness. ■

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