The Kindest Job in the World!

by Jim Nelson

On one long-ago day, we stood in front of a preacher and uttered "…'till death do us part…." We meant it at the time, but who could have envisioned the situation that we found ourselves in? Over the years, we have taken turns playing nurse, helping out, taking over sometimes really unfamiliar roles while the other one healed from some random hurt. Thing is, we always healed.

There are two kinds of maladies. Acute illnesses or injuries vary in severity and oft-times come on suddenly. It may take a cast or chemotherapy or just time; but both parties, the patient and the spouse, know that they are normally curable.

On the other hand, chronic means forever. Chronic conditions do not go away. They have no cure, nothing that will heal them, nothing to look forward to but many months — perhaps many years — of illness, of deterioration.

about the author…

Jim Nelson is a retired accountant and COPD patient. Both he and his wife Mary teach the value of humor and a good attitude.

However, it can also bring about one of the strongest, sweetest, most astounding relationships known to man; that of the patient and the caregiver. The fate of a caregiver can be that of a life put on hold. Taking over the responsibilities of the care of a fellow human being takes a really special kind of love. If the patient has some manner of serious acute condition, a condition that is likely to kill them very soon, it is easy to summon up the generosity to volunteer for the caregiver's role. After all, regardless of the degree of involvement, it is not likely to last very long. There will always be the sense of self-satisfaction, the admiration of others. As wrong as it may seem, it makes it easier to put oneself in the position of sacrifice.

The caregiver for the patient with a chronic illness — with COPD or MS or ALS — is faced with both certainty and uncertainty. They can be certain that their efforts will grow more complex, more onerous, more time-consuming as the disease progresses. The major uncertainty involves time. It can be a lonely business, knowing that the burden of care may last for many years.

That is assuming that the relationship is looked upon as a burden. Sometimes it is. However, there is also the loving relationship of which we spoke earlier. The third party in the relationship, the chronic condition that can threaten the status quo, can be very strong. Consequently, the willingness to sacrifice time, to put aside a life for another, so often comes from love.

My wife of 51 years has been a hospice volunteer for 20 years. She has had the honor to be with so many families, so many patients and their caregivers over the years. She has always been a kind, patient counselor, a healer.

Lucky for me

Due to several factors, including the sins of my youth, I was diagnosed with severe COPD at age 55. Suddenly, there was a reason for my perpetually weak lungs. Suddenly, I was the patient and Mary was the caregiver. Suddenly, our relationship took on a whole new aspect. We knew that as the disease took over my breathing, my life, Mary would be saddled with more of the duties of our existence. That's how it works. As time passed, we learned as much as we could about lung disease. We became involved with the American Lung Association and the COPD Foundation. We developed and taught classes to others on living with lung disorders. We tried to keep as active as possible. Nonetheless, the disease continued to take its toll; and it was becoming obvious that I was approaching the stage where hospice care would be indicated.

We both knew of the value of the hospice organization, of the incredible support offered by the medical staff, by the counselors, by the volunteers. They do not take the place of the caregiver. Rather, they supply support, assistance, and respite from the constant responsibilities. They give advice, a sympathetic ear, a shoulder to cry on. For the patient, they offer comfort, freedom from pain, dignity. We also knew that hospice is, in way too many cases, called

Jim and Mary Nelson

too late. The mistaken notion that calling hospice is "giving up" keeps too many people away from the services that could do so much good for everyone involved.

The only cure for COPD is a double lung transplant. In December of 2011, I was blessed with a new set of lungs! Mary and I are still teaching the classes and working with lung patients, and she is still active with hospice. Life is good. Told you I was lucky!

RTs impressed us

"One of the banes of the existence of COPD patients is the exacerbation, the lung infection, the pneumonia that knocks them down so badly. It brings on a choice: fighting through the increased weakness and shortness of breath to regain a semblance of their former quality of life or simply accepting their newfound disability. It was such an episode that first led me to the respiratory therapy unit at St. Joseph's Hospital in Tucson. They were a wealth of information, of guidance, of encouragement! I was so impressed with them that Mary and I eventually became a part of their educational program, teaching patients and caregivers how to deal with their disease. To our great delight, we have also become a part of the teaching process at Pima Medical Center, offering our story and guidance to RT students." ■