

Perspective

PATIENT LETTER

A What?



By the summer of 2010, our work in rehabilitating and marketing my wife's deceased parents' home was completed. The task, lasting several months due much in part to the 5-h driving distance involved, had been physically and mentally exhausting, more so given my deteriorating physical condition. Now, after repeated delays, we were finally able to meet with the Heart Failure/Heart Transplant group at the University of Florida Shands Hospital in Gainesville.

By this point in the progression of my heart failure journey, I was coming to the realization that my medication regimen was taking me about as far as it could and that my situation was entering a critical juncture, something I would now recognize as moving from stage 3 heart failure into stage 4, or end stage.

Every aspect of my life was being affected. Normal daily activities such as bathing and household chores were exhausting. Sleeping for more than an hour or two at a time was next to impossible because of fluid buildup in my lungs. Perhaps worst of all, my appetite for solid food was all but gone owing to an increasing failure of my digestive system. Poor nutrition and diminished blood supply were no doubt contributing to my overall decline.

So we, my wife Cathie and I, went to UF Shands in the hope of exploring the possibility of a heart transplant. Had it not been for Cathie's untiring efforts to find a way to keep me above ground, the meeting with Dr. Juan Aranda, cardiologist and program director, would probably not have occurred. The importance for a critically ill patient to have a stalwart, persistent, and informed advocate and caregiver cannot be overestimated. Without her untiring efforts, there is little doubt that I would not be here writing this today.

We first met with Dr. Aranda in early August 2010. After an initial discussion and examination, and some preliminary testing, the conversation took an unexpected turn. Although he did not initially rule out the possibility of a heart transplant he broached the subject that I might be a good candidate for a left ventricular assist device (LVAD). "A what?" I replied. "What the heck is an LVAD?" As it turned out, this

conversation was the beginning of what is now an almost 7-year epic adventure. To add a bit of perspective, at that time we had an infant grandson and one more on the way. Today we have 3 grandkids, ages 8, 7, and 4, who love their "Papa" and who would have never known me had it not been for my LVAD, the heart failure team at UF Shands, and my very determined wife who got me there in the first place.

From the outset, Dr. Aranda began to gently steer us away from discussion about a heart transplant toward consideration of this "LVAD thing." Because of my O positive blood type and that I am above average in body size, my wait for a suitable donor heart might be up to 2 years or more and that, for someone my age, the effects of immunosuppression drugs could be devastating to my overall health. That, coupled with the prospects of having to live in Gainesville, 100 miles from home, was a deterrent away from transplantation. In addition, during this time we became aware of a well-known public figure, former Vice President Dick Cheney, who was my age, and his apparently successful LVAD implantation.

Later that August I entered UF Shands Medical Center for 5 days of very thorough screening, going from one test after another. Unexpectedly a red flag was raised. A "lesion" was noted on my left kidney and the medical consensus was that it was likely malignant, making a heart transplant now out of the equation.

I had entered the hospital on a Monday weighing 191 pounds, about 10 pounds below my usual weight, and left on Friday weighing 173 pounds, that after a course of intravenously administered diuretics that kept me up all night filling up so many plastic urinals that I lost count. Although somewhat malnourished, the draining off of all that excess retained fluid helped me to feel better.

After being discharged on Friday, I spent a restless weekend knowing that a medical review board would meet the following Monday and would decide on a recommended course of action, or not. Monday afternoon I got a call advising me that I had been approved for an LVAD, something called a HeartMate II, if I wanted to go forward. For us it was an easy, live or die, decision.

The date of September 17th, a Friday, was set for me to check in to the hospital, with surgery scheduled for Monday, September 20th, the day we now refer to as my re-birthday. The next 2 weeks are now a blur in my

memory, except for 1 thing. A couple of hours before we were packed and heading to Gainesville, I remember getting into my backyard pool and paddling around for a few minutes, savoring the moment and thinking that this is the last time I will ever be able to do this. The adventure was about to begin.

Continuation from the patient letters in the August and September 2017 issues.

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Please note: Mr. Tatum has reported that he has no relationships relevant to the contents of this paper to disclose.