

Perspective

LIVING WITH HEART FAILURE

To ‘Plant or Not to ‘Plant, That Is the Question



I received the HeartMate 3 (Abbott) left ventricular assist device (LVAD) on June 29, 2019. A few months ago, I had a “heart-to-heart” (pun totally intended) with my primary cardiologist at the University of North Carolina (UNC) Transplant Clinic. The issue we discussed was one that I have been thinking about for the past 2 and a half years.

I want to preface this before going any further with full disclosure, I am *not* advocating a decision I made for myself to influence others. This decision is extremely personal, and it is imperative that everyone discuss this with their loved ones and family members before arriving at a decision.

What is this issue? My cardiologist said she needed to know my decision regarding heart transplantation.

After 2 and a half years of thought, speaking with family and loved ones, as well as with my primary caregiver, I have opted to not be listed for a heart transplant. My reasons for arriving at this point are as follows:

1. As anyone who has an LVAD, right ventricular assist device, or biventricular assist device knows, there are challenges that come with having your chest cracked open like a walnut, then wired closed, and with as much as 6 months of healing time. The pain associated with the healing of one’s sternum is so intense that it really does “hurt to laugh.” I do not want to go through that again anytime soon. Furthermore, every time I have open heart surgery, the risk of getting an infection or worse becomes more prevalent. In my thought process, I accounted for the amount of open heart surgeries I will likely accumulate for my heart condition: the first one was the open heart surgery for the placement of my LVAD, the next if I elected for transplantation would be for the removal of the LVAD and the placement of the donor heart. This is already 2 open heart surgeries and, should a complication arise after the transplantation that

requires more open heart surgeries, then the risk of infection or worse will continue to escalate.

2. I do not want to have a heart transplant and take the chance that my body will reject the organ. One of the most common issues with having an organ transplant is that your body may not accept it. If I were to have a heart transplant and my body rejected the heart, then the only recourse I have is to stay in the hospital until another heart becomes available. I am aware that if I opt to have a heart transplant, I will never be able to have another LVAD, period, and that thought frightens me. I have done many things during my life, and I am not easily intimidated or frightened, but the thought of not having an LVAD to fall back on is something that frightens the hell out of me.
3. I realize the challenges associated with an LVAD, such as not being able to sit in a bathtub and always having to take a shower, not being able to swim (I was someone who lived on a lake and swam constantly), not being able to enjoy a boat ride or go horseback riding, even not running around in the rain being silly. Although the challenges, if you choose to see them that way, are many, the ability to be here and to write about these challenges because I have the HeartMate 3 LVAD is an incredibly precious gift.
4. In my opinion, the HeartMate 3 LVAD, in many instances, outperforms a donor heart. And, the fact that my heart surgeon indicated to me that if something goes amiss, she can go in and swap it out if need be—well, that in and of itself is a level of comfort that I need and appreciate.

As I stated at the beginning, this is a choice that best suits me, and a choice I did not come to easily. I would tell others who are considering this same decision to ensure they have a network of support in place, and do not be embarrassed to discuss this with family and loved ones as they, too, will want and need to be a part of your decision-making process.

When I was first notified that medication and diet would no longer work and that I needed to have an LVAD, I decided then without reservation that I would build a website and develop a Facebook page that would help others who were facing the same challenges as me. I have a lot more work to do to help others, and I will not risk my ability to do that. I understand not everyone knows how to build a website,

or start a dedicated Facebook page, but there are other things that all of us can do to assist those who are in need of care, love, direction, and understanding. I also give lectures, visit people in the hospital who have just had an LVAD implanted, and sit on the board of advisors for the UNC Cardiology Department. One of the things I am most proud of is being an Ambassador for the HeartMate 3 LVAD. This appointment has given me the ability to reach out to so many people if for no other reason than to help others learn how to “normalize” what they are going through and how to get back to their lives.

***Rickey Esto**

*600 Stoney Creek Drive

Reidsville, North Carolina 27320, USA

E-mail: rickeysean@gmail.com

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