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# When Patients get **The Call**

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Waitlisted. Placed in a holding pattern. Physically restricted due to symptoms related to heart failure. Geographically restricted in order to drive to the hospital quickly when “the call” is received. Waiting for the opportunity for another chance at life. . .

Some heart failure patients live with the uncomfortable and unfathomable reality of waiting for someone to die in order to receive a second chance at life for days; some live this way for months, some – for years. Several patients on the heart transplant list require a mechanical device implanted into their heart called a Left Ventricular Assist Device (LVAD) because they are too sick to wait for a new heart. This device is life-altering in that the patient requires external equipment at their side at all times to maintain it despite the LVAD being a fully implanted device in the patient’s heart. As expected, significant lifestyle changes come with the implantation of an LVAD. A second or third chance at life hangs in the balance for the advanced heart failure patient or LVAD patient waiting for a heart transplant.

The heart transplant coordinator plays a significant role in coordinating the setup of the heart transplant procurement and surgery. From reviewing the donor heart and discussing with the cardiothoracic

surgeon and heart failure doctor, setting up transportation for the medical personnel involved in the procurement, to notifying all pertinent players involved in the surgery, the heart transplant coordinators all would agree that the most gratifying part of the process – next to a successful outcome – is getting to make that phone call to the patient to inform him or her that a perfect heart is available. The phone call usually contains a question along the lines of, “Do you have plans today?” The coordinators have received all sorts of answers: “I am just driving home from a short vacation,” “I have no plans at all,” and “Well, I was about to go skydiving!” Despite what plans the patient had, getting that life-saving phone call takes priority. An initially annoyed “Why?” turns very quickly into screams of celebration and tears of joy from a mother when her son, phone in hand, yells across the room, “Mom! You’re not going to work today. I’m getting a heart transplant!” Joy. Relief. Sadness. Anxiety. Grief. Happiness. Peace. These are just a handful of the emotions a



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Former LVAD patient, Marcelle Cass, received his Heart Transplant on 9/27/2019. Pictured with Marcelle is his mother during a clinic visit in December 2019.



Marcelle Cass with his Heart Transplant/VAD coordinator, Maggie Mendenhall.

person feels when undergoing this process, from start to finish. Many patients request “a minute” to process everything going on inside while on the phone with the coordinator when that phone call initially happens. In reality, patients need months or years to truly reconcile the emotions that surround receiving such an enormous gift another person has freely given. The graciousness of a donor is what helps the majority of patients live well with the new heart and new chance at life they have been given in order to be a good steward of this unexpected gift. Each heart transplant team member at the University of California, San Diego (UCSD) has their own unique and important place in the lives of these patients. The honor that comes with being involved in this amazing field of medicine takes on a whole new meaning when a patient affirms the work done by each team member and shows overwhelming gratitude for all they meet. As one patient has

said, “This is not just like winning the lottery, although many compare it to that. This is more than that. This is my life.” Oftentimes patients are asked, “Do you feel any differently?” or “What does your new heart feel like inside your chest?” Heart transplant recipients will crave foods they previously hated, or hate foods they previously craved. They will feel an urge to try new things they previously had no desire to try. Some just say, “I feel different” without any words to describe what is happening within. However, one patient is very descriptive of her new heart. She says, “It feels incredible. I can feel the beating more than I ever remember feeling my own heart. It feels warm, strong and consistent.” As UCSD continues to transplant growing numbers of patients with heart disease, more and more lives will be saved and more and more families will remain whole. Our goal in this overwhelming and arduous journey for all of the heart transplant

recipients is to be just as our patient has described: Warm. Strong. Consistent. If the UCSD heart transplant team is able to serve with compassion, strength and consistency, many more years of joy and second chances are inevitable for each of these heart transplant patients.