At just 24 years old, fraternal twins Edwin and Edward learned how quickly and intensely life can change.

After two weeks of feeling ill, Edward went to the emergency room – his diagnosis was heart failure. Doctors stabilized him with medications and he was released a few days later.

The diagnosis didn’t surprise brother Edwin; who was diagnosed with heart failure six years earlier. What did surprise him was how quickly his brother’s health declined. Within a month, Edward was implanted with the HeartMate 3™ LVAD to save his life.

“It didn’t think it would happen that way. Edward has always been the healthy one and I’ve been living with heart failure for such a long time. It didn’t seem real,” said Edwin.

Leading up to Edward’s sudden illness, the twins were working at a restaurant up to 60 hours a week – things would have to change.

“As Edward recovered, I was his caregiver, but I was only able to be there in the mornings and after work,” said Edwin. To bridge the gap, their older sister and an aunt helped Edward during the day. It was a challenging time for Edwin who wanted to be present for his brother as much as possible.

“It’s really tough being a patient, and the best thing I found I could do for my brother was to just be there,” said Edwin.

And then, during Edward’s recovery, Edwin’s heart health also began to deteriorate. His doctors advised he would likely need an LVAD. A right heart catheterization confirmed the prognosis, and just three months after his twin, Edwin was also implanted with the HeartMate 3 LVAD.

Several months later, the brothers have returned to regular life. They’re both back to work at the restaurant, although they’ve cut back to 40 hours a week.

As of today, the twins are not in a rush to get placed on the transplant list, and readily tell others that getting the LVAD was totally worth it.

Of life with their HeartMate 3 LVADs, the brothers say: “We are on a very unique journey together and we are grateful that we can be here for each other.”
LVADs for Life

HOW DO YOU WEAR YOUR LVAD? (PART II)

Last fall, inspired by your input, we featured some HeartMate LVAD™ Ambassadors sharing the creative ways they wear their equipment. Your feedback was so positive that we’re doing it again! Here are more of your peers, and the ways they wear their gear.

PUBLIC SPEAKING

Tonya is an advocate for women and heart health, both locally and nationally. Being so active, Tonya has developed multiple ways she likes to wear her accessories. “When I’m speaking publicly – sharing my story – I like to wear the vest I was given by the hospital because it exposes the equipment clearly as I explain what it does. If the occasion calls for me to dress up, I generally place all of my ‘accessories’ in a cute purse and wear it cross body. Sometimes I use a fanny pack, and recently I’ve been using a mini backpack, as was shown to me by a local Congresswoman who is also on support. So really, I feel like I have a lot of great options.”

ON THE GO PARENT

Already a busy parent of a rambunctious three-year-old, Bouba’s life went next-level with the arrival of twins. Since receiving his HeartMate 3™ LVAD, Bouba has favored wearing a harness vest - with a battery in each side pocket and the controller worn at his waist. But when the twins came, he realized some customization was needed.

“When I’m holding the babies, I want them close to my heart. But when we’re out and about, I want the equipment close when we’re on the go, and I can loosen it so the babies can lay closer to my heart.”

WHAT LVAD?

Heart failure survivor, Bill – with both his father and his son, Bradley – participated in a Heart Walk in their local Florida community. Florida can be hot and humid so Bill wanted to ensure he would be comfortable during the walk.

“I found for me, the best formula for success was to house all my external equipment in a shoulder bag. I find this set-up to be something I can almost forget about. My son carried my extra batteries along the route, so that brought an extra level of comfort and safety. It was definitely a group effort and a great day!”

GOING GLAM

Last year, Mayra was invited to share her story at the American Heart Association’s New Jersey Chapter Heart Ball. An honor like that called for a special gown. But dresses were not something Mayra had been wearing in the ten years since she received her HeartMate II™ LVAD.

“When I first started shopping, I was looking for something that accommodated the LVAD but then I remembered a HeartMate LVAD sister of mine and how she carried a small backpack with her equipment in it and I thought I could do that too. I purchased a really cute black backpack and modified it by cutting a hole in the side where I could slide my equipment in and then I used Velcro to seal it. Now I could wear whatever I wanted. I wore the most beautiful gown and simply ran my driveline up under my arm and out the side of the dress and into the backpack. The gown looked perfect with the backpack and I had the most magical night with my family by my side.”

In Care of Caregivers

DEAR CAREGIVER, PLEASE TAKE CARE OF YOU TOO

Caring for loved ones can be physically and emotionally taxing, especially if you’re not taking good care of yourself.

Maybe you’re not sleeping enough, not eating well, getting any exercise, or much time for yourself. It’s easy to lose sight of your needs when focused on those of others, but a lack of self-care isn’t good for anyone. The American Association for Heart Failure Nurses has created six steps to better Care for the Caregivers of heart failure, CARE HF®.

Care for yourself: Eat a healthy diet and aim for 7-8 hours of sleep every night. When you feel nourished and rested, you’ll be a better caregiver.

Be Active: Walk outside for 30 minutes every day or at least several times per week. Fresh air can make you feel better, sleep better and reduce stress.

Reclaim some of your time: See a friend, read a book, get a haircut, etc. Doing things you enjoy feels good.

Engage others: Seek help from family, friends or neighbors. Besides easing your burden, you and your loved one may appreciate the company.

Have Pride: Be proud of what you’re doing and the courage it takes to do it.

Find resources: Know where you can go to learn more about heart failure, caregiving, or both.

Prioritizing your needs and caring for yourself is the most important – and most forgotten thing – a caregiver can do. We’re at our best when we feel our best. You are wonderful, so treat yourself that way!*

*Adapted from: https://www.aahfn.org/page/caregiver

Meet a Caregiver

TRINA – DEVOTED DAUGHTER AND CAREGIVER

Why is being your mother’s caregiver an important role for you?

“My mom raised strong, independent daughters – by herself. When she got sick with heart failure, our roles reversed and we took on the caregiver role. For me, there’s a sense of family and legacy, and it is my honor because she was a strong woman for us.”

How does being a caregiver impact your life?

“A diagnosis of heart failure is a game changer and everyone in the family has to do their part. We made adjustments, starting with asking our children and families to step up at home so we could be there for our mom. We wanted her to have a quality life, not just an existence. Since the LVAD, she’s feeling optimistic, so we’re feeling good and positive.”

In what ways do you take care of yourself?

“I take a moment for a deep breath – to settle myself before I enter the room. This ensures I have on the strongest, calmest face possible. My faith plays a huge role in keeping me centered, and I exercise and meditate regularly. Keep in mind that you are your main source of support, so if you’re feeling good and positive, they’re positive.”

What message do you have for caregivers like yourself?

“Rely on something greater than yourself. I found that you have to find a ‘why’ – some purpose in caring for them. Yes, you will have hard days, bad days, sad days and uncertain days but that’s part of the journey. When you notice you’re making a difference, it gives you a sense of purpose and that “oomph” you need to keep going. Anytime I feel uncertain or tired, I remember she was always there for me.”

Each testimonial relates an account of an individual’s response to the treatment. The patient’s account is genuine, typical and documented. However, it does not provide any indication, guide, warranty or guarantee as to the response other persons may have to the treatment. Responses to the treatment discussed can and do vary and are specific to the individual patient. See Important Safety Information referenced within.
CONNECTING MORE HEARTS™

TO SUBSCRIBE, EMAIL YOUR NAME AND MAILING ADDRESS TO: HEARTMATEAMBASSADOR@ABBOTT.COM

The quarterly HeartMate™ LVAD Community Newsletter is for current or prospective HeartMate LVAD recipients and their caregivers. In it, you will find interviews with HeartMate LVAD Ambassadors, articles on life with an LVAD, caregiver-focused articles, and tips on things like traveling and exercising with an LVAD.

Individual Experience: Each testimonial relates an account of an individual’s response to the treatment. The patient’s account is genuine, typical and documented. However, it does not provide any indication, guide, warranty or guarantee as to the response other persons may have to the treatment. Responses to the treatment discussed can and do vary and are specific to the individual patient.

Important Safety Information
Rx Only

Brief Summary: Prior to using these devices, please review the Instructions For Use for a complete listing of indications, contraindications, warnings, precautions, potential adverse events and directions for use.

HeartMate III™ LVAS Indications: The HeartMate 3 Left Ventricular Assist System is indicated for providing short- and long-term mechanical circulatory support (e.g., as bridge to transplant or myocardial recovery, or destination therapy) in patients with advanced refractory left ventricular heart failure.

HeartMate II™ LVAS Indications: The HeartMate II Left Ventricular Assist System is indicated for use as a “bridge to transplantation” for cardiac transplant candidates who are at risk of imminent death from non-reversible left ventricular failure. It is also indicated for use in patients with New York Heart Association (NYHA) Class IIIb or IV end-stage left ventricular failure, who have received optimal medical therapy for at least 45 of the last 60 days, and who are not candidates for cardiac transplantation. The HeartMate II Left Ventricular Assist System is intended for use both inside and outside of the hospital, or for transportation of Left Ventricular Assist Device patients via ground ambulance, airplane, or helicopter.

HeartMate 3 and HeartMate II LVAS Contraindications: The HeartMate 3 and HeartMate II Left Ventricular Assist Systems are contraindicated for patients who cannot tolerate, or who are allergic to, anticoagulation therapy.

HeartMate 3 and HeartMate II LVAS Adverse Events: Adverse events that may be associated with the use of the HeartMate 3 or HeartMate II Left Ventricular Assist System include, but are not limited to those listed below: death, bleeding, cardiac arrhythmia, localized infection, right heart failure, respiratory failure, device malfunctions, driveline infection, renal dysfunction, sepsis, stroke, other neurological event (not stroke-related), hepatic dysfunction, psychiatric episode, venous thromboembolism, hypertension, arterial non-central nervous system (CNS), thromboembolism, pericardial fluid collection, pump pocket or pseudo pump pocket infection, myocardial infarction, wound dehiscence, hemolysis (not associated with suspected device thrombosis) and pump thrombosis.

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