

# PAYING IT FORWARD AFTER HEART FAILURE

Ray's Story



Ray and his wife Wini are the proud parents of 4 grown children and 6 grandchildren. A devoted family man, Ray loves spending time with them, but that was put at risk when he went into cardiac arrest in 2014 and was subsequently diagnosed with heart failure. Ray remembers how difficult this time was—for both him and Wini. Now, after surgery and continued work at

cardiac rehab, Ray is coaching Little League and volunteering with Mended Hearts® to help patients and their loved ones cope with heart disease diagnoses. Ray shares his journey with heart failure, how he pays it forward to help current patients, and why it's so important to support caregivers in coping with the stresses of a cardiac diagnosis.

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## What led to your diagnosis with heart failure?

Back in 2014, I was seeing a few doctors because I thought I had pneumonia that just wasn't getting better. One night, I couldn't sleep and told my wife I was going downstairs to sit in a chair. She insisted I go to the hospital instead. I was in disbelief when the doctor came into my room and told me I was in cardiac arrest. I thought he had the wrong room—I told him it was just pneumonia. He said I needed to have surgery for a new heart valve and sent me home to prepare and "put my affairs in order." I went from thinking I had pneumonia to having to go show Wini how to balance the checkbook in case I didn't make it through the surgery. Those conversations certainly put things in perspective.

Fortunately, I came through the procedure, but they couldn't fix the damage that had been done to my heart. I learned I had heart failure.

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## What was it like hearing this diagnosis?

When I heard "heart failure," my mind started racing. I asked myself, "What did I do wrong? How did I get this? Why me?" I think these are all normal questions to ask when you receive such a daunting diagnosis. I was completely shocked because I thought I was relatively healthy. But my heart wasn't.

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## What advice do you give people who are going through what you went through?

The most important advice I share with people coping with heart failure is to do what your doctor tells you, and collect as much information as you can about your condition.

I also tell them to pay special attention to their caregivers and loved ones because they're often the most scared people in the room. From my vantage point, the caregiver is usually just as shocked by the diagnosis as the patient.

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## How has having heart failure changed your life?

Going through something like this changes your perspective; you learn you're not immortal and you need to think about that. It's made me become less internally focused and more externally focused. For me, that's meant trying to help others. Since my diagnosis, I've coached Little League for my grandkids and become very active at church. And now I volunteer with Mended Hearts®, visiting people in the hospital who are newly diagnosed with heart disease.

This work is important to me because I remember what it's like to be in the hospital at 8 o'clock at night undergoing a bunch of tests. It's scary and lonely. For me, I felt like I was in a dark place where I had no control. When I go into the hospital to meet with patients and their families, I try to reassure them and share my story to provide living proof that they can get through it. When I was in the hospital, talking to others who had been through it helped me, and now I'm trying to pay it forward by being that person for others.

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## How do you think caregivers are impacted by a loved one's heart failure diagnosis?

I often find that caregivers struggle. I've seen them crying their eyes out because they think their loved ones are going to die or they're worried about how they'll support their loved ones through their illness. They're asking themselves, "What am I going to do? Can I go to the store without taking this person? Can I do this? Can I do that?" It's a real challenge for the caregiver, and many of us forget that.

I try to help the caregiver see the challenges ahead can be overcome, and I help them to be more positive, as that can bring a lot of good energy to the patient. I tell caregivers to just listen to the doctor and follow their lead.

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## How can caregivers support their loved ones?

It's really helpful when caregivers get involved in meetings with the doctor. I advise that they bring a notebook and take good notes about what the doctor has to say, and then help their loved one stick to the doctor's prescribed plan. To this day, if I look like I'm not going up the stairs the right way, I'll hear about it from my wife. She's always watching me to make sure I'm okay and pushing me to schedule an appointment if she thinks I need to get checked out.

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## What do you wish you had known when you were diagnosed?

I wish I'd known to ask more questions. I didn't know much about the heart—just what I remembered from high school biology. The doctor didn't share too much of what he was going to do beyond, "We're going to go in and fix it." I wish I'd known to look for information like *At the Heart of the Matter—Moving Forward After Your Heart Failure Hospitalization*, a program by Merck in collaboration with Mended Hearts®, which offers educational resources to help chronic heart failure patients after hospitalization with heart failure.

In addition to being more proactive in information seeking, I'd also tell myself not to be scared, and that you're going to make it through this. Trust your doctors, trust your support team, and talk to people who have been through it—like the folks at Mended Hearts®. You're not alone on this journey, and there's a lot of comfort in that.