

LIVING WITH A HEART FAILURE DIAGNOSIS

Robin's Story



As a former Director of Education, Robin was only 55 years old when she was diagnosed with heart failure. At the time, she was in overall good health and was shocked by the diagnosis. She's since learned that she has a family history of heart disease. After working with her doctors on a treatment plan and coming through

what she remembers as many "dark days," Robin now volunteers for Mended Hearts® to support others living with heart failure. She shares how she persevered and why she's passionate about helping others find the light, too.

Everyone living with heart failure has their own story, what's yours?

One morning I woke up and I couldn't get out of bed. I was nauseous and sweaty, and my hands and feet were tingling and numb. I didn't know what was wrong. My husband was away for work, so I called my parents to take me to the emergency room.

The last thing I remember before I passed out was being told I had heart failure, and then I was life flighted to a heart failure clinic. When I came to, I was completely disoriented and didn't really understand what was happening. They told me my heart wasn't working, and my mind did a double-take, thinking, "What did they just tell me?" I couldn't believe what they said.

How did you feel once you knew you had heart failure?

You know how when something bad happens to you in life, you sometimes forget about it during a night's sleep? And then it's like a fog when you wake up, and you think, "No, that bad thing didn't happen. It was just a dream." That's how it was for me. It was hard to wrap my head around this shocking diagnosis and hear that I might die. I think I made it through those first few tough hours by putting the fear aside and listening to my doctors. I trusted that they could bring me through it.

At first, my doctors thought I might need a transplant but then they decided I might be a candidate for a new device that could help improve my heart's function. That sounded much better to me, so I did everything they told me to get my body and heart strong enough for surgery. Fortunately, it worked and I was able to have the surgery just after Christmas in 2016.

How did you feel after the surgery?

It was a long road to regain my strength. I had to learn how to do everything over again, starting with the simplest task of sitting up in bed. Following my doctor's advice, I stuck to a strict regimen of diet, medicine, and exercising as much as I could. I began with rubber-band stretches to strengthen my muscles. Then I transitioned to light weights on my legs and hands. Slowly, I was allowed to walk to the mailbox and take a light bike ride, and eventually I was able to start mild paddleboarding and slow swimming again.

I knew my healthcare team was helping me save my life, so I did everything to follow their instructions—to help them help me so I could be there for my children and grandchildren.

Did you have difficult days while you were trying to rebuild your strength?

There were some really dark days, trying to cope with the emotions of anger—the "why me" questions. One of the hardest things to overcome was the tiredness—the sheer exhaustion that made me want to give up because I was so physically weak and tired. But I wasn't going to quit because I wanted to be there for my grandchildren. I forced myself to push forward, keeping the negative thoughts at bay and staying focused on getting stronger.

How has heart failure impacted your day-to-day life?

The biggest impact is that I'm not able to do all the things that I could do before. For example, I used to run, but now I can't because it puts too much stress on my heart. No more marathons or climbing the stairs of the Empire State Building.

The good news is there are still activities that I can still do and enjoy. I try to walk each day and sometimes go for a light bike ride, swimming, or mild paddleboarding. I also try to follow my doctor's advice to eat a more heart-healthy diet now, which means lean meats and plant-based foods like kale, sweet potatoes, and papaya.

What advice would you give to someone who has just been diagnosed with heart failure?

As a volunteer with Mended Hearts®, I meet with a lot of people who are newly diagnosed, and I always tell them to follow their prescribed treatment plan to help their doctor help them get better. I also tell them to hold onto hope and stay positive. Don't let little things get under your skin. There will be days when you're tired, and you'll need to sit down and rest. But don't let this weigh you down. If you don't accomplish all you want to do in a day, it'll still be there waiting for you tomorrow. You just have to focus on what you can still do because there is so much to enjoy in this life.

What inspires you to keep pushing ahead?

My children and grandchildren are my greatest inspiration. I try to set a good example, showing them that even though life is hard sometimes, you can get through it by building inner strength and finding reasons to be thankful.

I'm thankful to all the people who came before me and participated in the heart failure research that has made today's treatments possible. Without them, I may not be here. It just gives me chills to think about it. They helped to give me a second chance, and I try to use this gift by giving back and supporting other people with heart failure. If I can help one patient find the strength and fortitude for their recovery, that's what I want to do.