

## Patient Perspective

### LIVING WITH HEART FAILURE

#### Doctor's Orders for Being Lost in a Low-Sodium Diet



My name is Regina, and I have heart failure. That sounds like I've just been to a support group meeting because I've just been diagnosed with heart failure or "heart disease." Now what? That couldn't be farther from the truth, so let's start my introduction over. My name is Regina. I have always been and still am short and petite. I am not a "typical" heart patient; I am only 49 years old, I weigh 111 pounds; I am a thin white woman who exercises and who strives constantly to maintain balanced and healthy eating habits.

Before my heart failure, I was faced with a lot of medical challenges: multiple congenital abnormalities with a very distinct murmur (I love watching new doctors listen to it), ventricular septal defect, an imperforate anus with rectovaginal fistula (in which an artificial implantable artificial sphincter muscle device was implanted as a young adult), and a variation of Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome. I am a complicated patient—someone walking on a tightrope. One bad decision or medicine can tip me off that tightrope.

From my open-heart surgery in second grade until becoming a young professional in 1998, I was blessed with no complications and not burdened with any medications. The only restrictions were set by me. I did a lot, including riding roller coasters, which I loved. Through my family's love, prayers, and support and having a team of great doctors, I managed to live a somewhat normal life. It can be challenging to find a someone who loves you and will accept all the medical baggage brought along, but John found me, and we were married in 1994. We later adopted 2 children. One morning not long after our son's birth, I became very dizzy, prompting a pulmonic valvuloplasty, which came totally out of the blue.

Years passed again without any real restrictions or daily medication. However, in 2006, I had a bout of ascites. We thought for sure it was my heart, but a series of tests determined that I had ovarian cancer. Up until that point, I had felt very comfortable with

my heart and bowel issues—and my trusted doctors. The Riley Hospital doctors who managed care of my heart and colon and rectal conditions during my childhood were wonderful quarterbacks. Dr. Roger Hurwitz, cardiologist, and Dr. Jay Grosfeld, CRS, were wonderful instructors for new interns, as well as being very respected as masters in their fields. I can remember feeling like a "star" as the doctors and interns crowded into the examination room and discussed my prognosis and sometimes held a quick question-and-answer session. Now, as an adult, I would meet several new types of doctors. I always accepted that it would be my heart that would eventually send me to Heaven. Now, there was a risk of something much worse. After I underwent exploratory surgery, no cancer was detected; and after recovering from that surgery, the fluid continued to build. Finally, my heart did show up as the culprit.

A dual-chamber insertable cardioverter-defibrillator was implanted by Dr. Benzy Padanilam. He introduced me to Dr. Mary Walsh, who specializes in heart failure. I thought, "I don't really have 'heart failure'?" I didn't feel that bad. It wasn't like I was on my last breath or anything. We spoke about what that really meant, and again she echoed the "low sodium" diet plan. I said, "Okay, I'll stop adding salt to my foods." However, this is not how it works, as you know. I tried to watch my eating habits more carefully but continued to eat out frequently, not worrying about anything. Anyway I felt that my condition was a result of stress.

Unfortunately, in the summer of 2015, my ascites came back, and I went to see Dr. Walsh. I explained that I didn't understand that, even though I had been working out and watching what I ate, I still gained fluid and continued to lose muscle tone. My stomach looked like I was going to have a baby. I missed several days of work. It became very noticeable that I had started to see these new heart doctors a little too often. Dr. Walsh ordered that I be admitted for tests and a paracentesis again. I always feel terrible after a fluid drain, while the organs moved back to their original locations. It feels like when I had just gotten off the "Son of Beast" roller coaster at Kings Island when I was younger. When it was okay to go home, I was 10 pounds lighter! The doctors felt it best that I remain on a medical leave until basically the end of October, to rest and allow the changes they had made in the medicine routine to stabilize.

Often, I have felt as if God calls me to go on a “retreat” with Him during my stay at the hospital and now on “medical leave.” I have time to reflect on my life and where I have failed to trust Him and be like Him. Back home, during the day, I began digging a bit deeper into this low-sodium thing. I sat in my kitchen planning meals, using the new food scale I bought, listening to quiet music. I also tried to take naps on the deck in the warm sun. It was nice, but I like to be busy, so this has settled me down a bit. I had also taken time to attend morning Mass, and I began exercising more consistently.

Also, in this new found spare time, I continued to update my medical life in what I call my “Operators Manual.” This manual has grown and comes in handy as a reference when meeting new doctors or having the cumbersome task of filling out medical history forms every time I turn around, it seems. It also seems somewhat amazing when I look back through the manual to recap my own life and try to remember what I’ve been through as I write stories as well as facts.

I was informed that I now had “low sodium” in my blood. And, I had all the classic symptoms of weakness, fatigue, muscle cramps, and irritability. When I initially started my low-sodium diet, I had been on an intensive diuretic agent every day to assist in the fluid loss—this ended up complicating the balance of my electrolytes. Come to find out, eating a low-sodium diet has nothing to do with having low sodium in your blood! To be honest, this is complicated to learn, understand, and explain. (I am still trying to find someone who can explain it to me.)

To combat this new problem, I was put on a “fluid-restricted diet.” What? Now, I can only have 48 oz of fluid a day—that includes soup and ice cream, because when ice cream melts, it becomes a fluid. My diet consists now of 1,500 mg of sodium per day and 48 oz of fluid a day. What else could I be restricted from now?

During a follow-up meeting with Dr. Walsh, she told me straight out, “Regina, you have right-sided heart failure with ascites. This is just something you will have to learn to accept and manage. It may be due to the congenital heart defects that your heart is now having a hard time keeping up. There is no real “fix” for this, but do keep on doing what you are doing. And, we will keep monitoring you. Just think what you may feel and look like if you weren’t diligent in watching your sodium intake.”

If I abide by orders, taking into account my other medical challenges, my daily menu looks awful and complicated:

- 1,500 mg of sodium;
- 48 oz. of fluid;
- No (or very little) vitamin K because of the Coumadin I take;
- Calcium intake, because now I also have osteoporosis;
- Potassium intake, because I’ve been known to go too low or too high;
- High fiber for bowel issues;
- Taking Imodium and eating foods that reduce the risk of incontinence issues.

So, my goal is to maintain the 1,500- to 2,000-mg sodium allowance, which, I’m thinking, I may then not have to worry so much about the fluid, although, I’d have to say I think the 48 oz of fluid is the hardest to overcome at this point. I think about my typical day, which consists of 8 oz of water, which would include taking my medicines in the morning and evening; 8 oz of orange juice to get my potassium; 8 oz of milk for calcium; 12 oz of Coke (because I like Coke!); and 8 oz. of water (because water is better for you). And that only leaves approximately 4 oz for wine or a drink in the evening, at which point, why bother? I’m not necessarily a “woe-is-me” person. I have accepted what I was dealt, with faith. I can think of many people who have it a lot worse than I do.

Recently I have downloaded several apps that help me track different aspects of my medical life. My health folder on my iPhone has almost as many apps as my social media folder. All that sounds good, right? You might be thinking, “She has really gotten on top of it. Good for her. She’s now a ‘star’ patient! If everyone was as diligent as she, we’d be out of a job.” Well, obviously, that isn’t the case, and even for me, who knows better, it’s still hard to remain dedicated. If you looked at my app history today, it would be lacking several days or even weeks. Some of these apps are not very user friendly, especially the sodium-tracking apps I’ve tried.

I began blogging off and on in 2015. I think I started doing it more for me, to continue to document my health history, rather than to keep it private. I’ve always liked to entertain my friends and family with stories from the hospital, starting all the way back in second grade. Adding a bit of humor makes it a lot less scary for everyone. I’ve never felt the need to be a part of a support group (I’ve had such a strong network), but recently I’ve gotten involved with WomenHeart, and it does make me happy to help others get through tough times.

At any rate, living with heart failure really isn’t what defines who I am. It’s just a part of what makes

me who I am. I have been blessed over and over with great family and friends, who have been there to listen and learn from my experiences during all phases of my life. I'm not doing bad for a 49-year-old, 111-lb, 4-foot 10-inch woman who wants to feel like she's still 26, and has an internal body like a senior citizen, which also now includes osteoporosis.

I have at least a few more stories to tell, hopefully, when I'm a lot older. Life is too short not to laugh through the struggles. Recently, I asked my 16-year-old daughter what it was like to live with a mom with heart failure. Quick wit that she is, her answer was,

"It sucks. But, don't say that; people will think I'm heartless."

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