

# TRANSCRIPTION

**cpsi Canadian Patient Safety Institute**  
**iscp Institut canadien pour la sécurité des patients**  
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**[0:00:06]** I owned a business school. I worked about 60 hours a week. And I continued working. I was 43 at the time and I started having a few things going wrong. I was sweating a lot. I was congested a lot. I was tired. I was having trouble with my energy level. So I was seeing my doctor fairly regularly, being sent to specialists. They sent me to an allergist and though they couldn't find any signs of an allergy. They swore I was allergic to my new dog. I was walking up a street hill and I got to my office and I put my head down and it took me half an hour to catch my breath. And I thought, "This isn't right."

**[0:00:59]** So I went to the doctor and said, "You know what? I don't know what we've done for the last year, but right now, I think I have bronchitis. I think that there's something wrong." So she checked me and she listened to my heart and she tapped my back and she asked questions and she sent me home and said, "You don't even have bronchitis. You've just got a bad cold."

**[0:01:22]** So I went back to work and everybody left me alone for a day and then the next day somebody walked up to me and said, "You know what? Something's really wrong and you have to go ask for a chest X-ray." so I did, and I didn't feel well so I came home a bit early and I had a message on the phone. "Can you go and get yourself an ECG in the morning?" So the next morning, I went and got myself an ECG at the satellite lab, and they very calmly gave me a file and said, "Would you like to go see a doctor over at the hospital?" And they looked at it and put me on the bed and a doctor came in and said, "You're in heart failure and we don't know what's wrong." And that was the start of things that could go wrong, did go wrong.

**[0:02:10]** So first of all, a whole year of being misdiagnosed and ending up in heart failure but sitting in the bed that day, I realized that my grandmother and my mother had both died before they were 40, suddenly, of heart failure. And I knew that and I told every doctor I knew that. I used to ask for stress tests whenever I had a new doctor. And I realized that nobody had really taken that into consideration the whole year I was giving them all these symptoms.

**[0:02:47]** So they stabilized me for a week in the hospital and then they made an appointment for me to see a cardiologist in St. Paul's Hospital.

**[0:02:59]** What happens to the heart when you're in heart failure is the heart enlarges and as it enlarges, it becomes more inefficient so it's not able to pump efficiently. Your ejection

fraction is the amount of blood the left ventricle is able to pump out into the body every time it beats. And your ejection fraction should be 60%. So 60% of what's in that ventricle should be going out to your body. When I when I was in heart failure, it was 20%.

**[0:03:36]** And then they sat down with me and told me that they had just really discovered that your heart can actually recover if they're able to slow my heart down and lower my blood pressure with meds. So they put me on alpha and beta blockers, very high doses, slowly up to a very high dose of it, and they put me on ace inhibitors, and they put me on diuretics, and they gave me anti-anxiety pills, and I went to sleep. And I mean, I went to sleep. I was in bed probably 22 hours out of 24 a day. And the only reason I even got up was because my son was home from school. If I wasn't dressed and sitting up looking like Mom, he was scared.

**[0:04:23]** This treatment actually worked phenomenally well. When I went back to the cardiologist within a year, my ejection fraction was back up to 50. And within a year after that, it was at 60. So it was, hooray, this is great.

**[0:04:45]** Now that we have me recovered and all and on all the right antidepressants and anxiety drugs and heart medications, the next step was to try to take me off some of them so that I wasn't dealing with that kind of fatigue all the time. I took that letter and my doctor took that letter and she said, "Okay, here we go. We start." We went down half a dose. And I started going in pretty much monthly, every 4 to 6 weeks, and get my blood pressure, get my medications.

**[0:05:21]** And within two years my husband said, "You look like you're swelling up again, like you've gained weight." So I went back to the doctor and said, "Do you think maybe I need to be back on a diuretic?" She says, "Well, maybe we should put you back on all your medications." And I said, "Oh, no, I don't want to go there. That scares me. I don't want that fatigue. just try me on a diuretic." So she did.

**[0:05:48]** In the meantime, I made an appointment with the cardiologist. And I walked back to the cardiologist and she was furious. My ejection fraction was 28%. And she said, "You've gone down way more on the meds than you were ever instructed." And it was this far away from heart failure. And it was the first time I realized that depending on my doctor was the worst thing I could do. And that scared me because I thought that when you were sick, you're supposed to depend on your doctor.

**[0:06:30]** So I changed doctors and I turned back into the business person I used to be before I was sick. I sat down and told her we needed an action plan and we needed to have follow-up and feedback and we needed to assign jobs and assign responsibilities and we needed to form a team and get back to each other. Unfortunately, the second time around, I wasn't as lucky because the damage was done. So now my ejection fraction is 45%, which is okay. It's livable. What's not easy is being on all the drugs.

**[0:07:16]** There's a big push going on now for patients, self-management of patients. And I really wanted to get it across that you can't really ask patients to self-manage them because that's a copout. That's not everybody taking ownership, because self-management means it's mine. And it's not mine. I'm not a medical professional. I have no idea what my body does, what it expects. And I want to see specialists and doctors playing closer to each other because I think that the two years where my cardiologist gave instructions to my doctor, had there been more of a teamwork going on, some follow up, some follow through, some action plans, that it would have been caught. There was no turning it around this time. There's no third chances for me.

**[0:08:17]** I thank God every day I'm alive. And I have lots of nursing friends who said I'm one of maybe three people they know who did live through this. So I know how lucky I am, but I don't always feel so lucky.

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