



The Beat - Episode 3 Final Transcript

The sacrifice and satisfaction of family caregiving

[00:00:01] **Debbie** My mother often said to me that things are only OK when you're here. And so that really resonated with me.

[00:00:10] **Heather** I just remember sitting on the floor in the kitchen and crying and crying and crying.

[00:00:20] **Caroline** Chances are you or someone you know has been personally affected by heart disease and stroke. They can devastate lives, sometimes suddenly. But there's hope. I'm Caroline Lavallée, and you're listening to The Beat, a podcast by Heart and Stroke with support from our generous donors. In each episode, we're joined by Canada's leading physicians and experts to discuss the most pressing issues related to heart and brain health, and you'll be inspired by the real stories from people living with heart disease and stroke. Thanks for listening. Now let's get into the episode. On the day someone leaves the hospital after a stroke or a serious heart attack, you'll almost always see someone carrying their belongings or pushing the wheelchair. This person likely just became a caregiver, and they will play an essential role in the recovery, rehabilitation and well-being of their loved one. Caregivers will spend hours of their day, often behind the scenes, doing work that will likely go unnoticed.

[00:01:31] **Jill** I use the term family caregiver, but I define it quite broadly. So it is a family member, a friend, a significant other who provides assistance to somebody generally in the community who is unable to fully care for themselves. So they're providing assistance, they're providing the support, they're helping them navigate the healthcare system by helping them with a whole host of activities, helping them to engage in their rehabilitation after a stroke, for example.

[00:02:04] **Caroline** That's Dr. Jill Cameron, a professor and vice chair research for the Department of Occupational Science and Occupational Therapy in the Temerty Faculty of Medicine at the University of Toronto. Dr. Cameron specializes in caregiver needs and support so we'll be hearing from her throughout the episode. Every family caregiver's circumstances and challenges are unique. Like Heather Lannon, who cared for her husband Jamie, or Debbie Benczkowski, who cared for both her aging parents. But all caregivers are needed in the fight against heart disease and stroke.

[00:02:44] **Heather** Jamie was diagnosed actually with a congenital heart defect when he was born. He was born with a condition called transposition of the great arteries. And when he was about a year old, he had corrective surgery to fix the problem. And at that time, it was in the 70s, they believed that he would go on and live a pretty normal life. And he did that for, you know, the remainder of his childhood, teenage years, young adult.

[00:03:13] **Caroline** This is Heather. She is Jamie's wife and was his caregiver. She now works with patients and families as an aortic coordinator in the Cardiovascular Surgery Department at St. Michael's Hospital in Toronto.

[00:03:26] **Heather** And then when he turned about 30, he started to have a lot of symptoms that we didn't know then was heart failure symptoms. But things like shortness of breath, inability to lie flat, inability to climb stairs, to go on long walks, vomiting, some swelling in the ankles, in the belly, that kind of thing. And nobody really knew what the problem was. We had gone back and forth to hospital many, many times in Newfoundland. And finally, after probably a couple of years of going back and forth, we heard this word heart failure.

[00:04:03] **Caroline** Newly married, Heather had recently graduated in social work and Jamie was a musician and teacher. While their friends would be starting to have families, build houses and pursue their careers, this young couple had to put their hopes and dreams on hold.

[00:04:20] **Heather** He was very ill. He was in the ICU and there was nothing that could be done for him in Newfoundland. They did not have the specialized care he needed. So we ended up coming to Toronto, and we were lucky enough that we could for a couple of years, get the treatment here and remain in Newfoundland. Eventually, a time came that Jamie's illness had progressed to the point where a transplant was needed, and we ended up making the move to Toronto so he could be close to the transplant team here.

[00:04:49] **Caroline** By leaving Newfoundland, Heather had to become Jamie's sole caregiver, 3,000 kilometres away from the help and support of their families.

[00:04:58] **Heather** I managed the medication, the doctor's appointments, the food, the restrictive diet, oh my God. And the fluid restriction was horrible, horrible to the point where I would masking tape bottles in the fridge so he wouldn't drink it. There's other things, like I don't even talk about measuring pee. Everything that went in, had to be measured. Everything that comes out has to be measured and recorded and wrote down and all that. There's just so much. I laugh about it now, but it was like a full-time job.

[00:05:29] **Caroline** This unexpected full-time job in a city that took Heather far away from home would last for the next three years. Even if you're not living with a loved one, 24 hours a day, seven days a week, you may still be their primary caregiver. Debbie Benczkowski lived 200 kilometres away from her aging parents, with the Canada U.S. border between them. And as their caregiver, she'd make frequent road trips from her home in Toronto to her mother and father's nursing home in Buffalo, New York.

[00:06:06] **Debbie** So I would leave on a Saturday morning, very early in the morning, and I would come home on a Sunday night if I was just going for the day. And early on, I often only went for the day. It would be, you know, 400 kilometres in a day driving back and forth. And if it was the summertime, the bridges were terrible and I might be another extra hour getting over the bridge. So that was always took a lot of time.

[00:06:31] **Caroline** Debbie started making more of these long cross-border trips after her mother's health started to decline in her 80s. If she wasn't in Buffalo, she was still providing care on the phone from her home or her office, at the charity where she worked.

[00:06:47] **Debbie** My mother lived a very healthy lifestyle and healthy life until her late 80s, when things started to fall apart for her. She developed diabetes and she had some other health challenges. She had a series of TIAs, and then she had quite a debilitating stroke that necessitated a different level of care and caregiving, a lot of which my dad was unable to provide. I was coordinating medical appointments if she had to go. I was coordinating medical appointments for my dad, if he had to go. So, you know, there was just a multitude of things, tons of phone calls back and forth, to my father, to my mother. And actually, when my mother lost the ability to remember how to use a phone, that got more difficult. A lot of phone calls every day, reassuring her, making her feel comfortable. She never liked being in the nursing home, so it was always difficult to talk to her on the phone.

[00:07:53] **Caroline** Heather and Debbie had taken on different caregiving roles, but their function was the same, being present physically and emotionally, so their loved ones weren't alone in their time of need. When a sudden illness affects a family member, being present is just the beginning.

[00:08:14] **Jill** When somebody has a stroke, a family member is going to very likely become a caregiver within days or weeks with no preparation. So it's really important to remember that the biggest challenge they face is they have not been prepared for this role. And as a result, it can become stressful. It can have a negative impact on their lives, on their health, on their well-being. And ultimately, if a caregiver isn't doing well, that can have a very negative impact on the person that they're caring for as well.

[00:08:52] **Caroline** As days turned into years, we know anxiety and depression can start to affect the mental health of people like Heather and Debbie. Put in situations with so many unknowns, the stress must be at times debilitating.

[00:09:08] **Debbie** I have to say that it was just it was a profound sadness all the time. I don't think I ever got away from that. So there was a sadness that my parents had to have these difficult years, and it really did turn out to be years. I would say there were 10 years where they really required a fair amount of support. Obviously, it escalated as time went on. It was always that sadness in the back.

[00:09:42] **Caroline** A sadness brought on by the personality changes that she witnessed in her mother, a result of vascular cognitive impairment caused by her stroke. Both Debbie and Heather did what they could to hold it together, even in the toughest of times. But the stress did take its toll.

[00:10:02] **Heather** We had been here, I want to say a couple of months. Jamie's health was continuing to deteriorate. He was in and out of hospital, back and forth to emerg. Nothing was working and we had rented a furnished condo here near the hospital. And after a long, long day at the hospital, I went home and was preparing dinner. And I can't remember what I was meeting making, but I needed a cheese grater to grate the cheese to put in this dish. And the apartment we were renting was sparsely, you know, equipped with dishes and things like that. There was no extras, just very minimal, and I couldn't find the cheese grater and I just remember sitting on the floor in the kitchen and crying and crying and crying. I don't know how long I sat there, but I had enough intuition that I phoned my mom and I was still crying. But she was so good and she was like, It has nothing to do with the cheese grater. And we talked for a while, and that was probably one of the more eye-opening moments of the stress and the pressure I was under.

[00:11:13] **Caroline** Facing the unknown is never easy. And when a loved one's life is at stake, it's not surprising that there comes a tipping point.

[00:11:23] **Heather** I think, you know, we're so caught up and so busy taking care of the person with the illness that we don't even really think sometimes. like, how is this affecting me? How am I doing? You know, am I feeling overwhelmed? Am I stressed? Am I sad? Am I worried?

[00:11:39] **Caroline** And there is more than just an emotional toll.

[00:11:43] **Jill** Caregiving can have a significant impact on the financial status of the caregiver. In some situations they will decrease or leave a paid employment situation, which has implications for their current income, but it also impacts their contributions to pensions so their future financial sustainability can be challenged. That's one side. Another side is that our health and social care systems don't cover financially all the expenses that you might have to keep somebody in the home after they've had a stroke, for example. So often times family members have to pay out of pocket for additional supports, for additional programs, for adjustments and adaptations to their house to be able to support somebody.

[00:12:39] **Heather** There was a lot of issues with the costs and the finances of just traveling back and forth. We were using, you know, a lot of our own finances, a lot of our vacation time and sick time and things like that from our employer was being used up for all these medical appointments.

[00:12:57] **Caroline** Financial sacrifices can be measured and calculated, but the strain on relationships with family and friends are more difficult to assess and can be harder on the caregiver's mental health.

[00:13:10] **Debbie** What caregiving took away from me was probably a social life. I didn't have much of a social life. Weekends were taken up with seeing my parents and making sure that everything was OK. So I don't regret that. My friends were very understanding and people knew that I was doing what I had to do to support my parents. So, you know, I did miss out on a lot of social things and my husband would go without me and you know, he would keep in touch with our friends from that perspective.

[00:13:45] **Heather** And seeing that my friends or my colleagues were all moving forward and I was stuck. I was just in the same spot, I struggled with that. And then the part for us that made it even more challenging was, we were thousands and thousands of miles away from everything. So my family, my mom, my dad, my sister were in Newfoundland. They were my huge support system. My friends who I had had since kindergarten were in Newfoundland. So everything that, you know, was familiar to me and comforting and safe was physically not there. So I struggled a lot with that in the beginning but then as time went on, I think you kind of adapt.

[00:14:37] **Caroline** When I came home from the hospital after heart surgery, the last thing I wanted was to be a burden on anyone. I wanted those that were helping me to still find time to live their lives, to keep doing the things they love to do. I think that's really important because if caregivers are not taking care of themselves or accepting help from others, it will only become more difficult to properly care for their loved one.

[00:15:07] **Jill** I like to think about caregivers as needing to be supported. And when I say they need to be supported, there is an element of emotional support to address their own emotional well-being. There is an element of informational support. They need information to be able to understand the illness, understand the care needs of the person, understand what services and programs might be available to them to help them keep the person at home to help support the caregiving role. So there's a big informational need. There's also training that caregivers need support, and so they need to learn how to provide care. If you think of somebody who has lost the ability to communicate, the family caregiver needs to learn new strategies of communication for a person with aphasia, for example. So there's an important training element. There's also situations where a caregiver just needs somebody to help them do something. So to help organize services, to help receive your home care supports, for example, somebody might need to just help them navigate the system a little bit more. And the other elements of support that I like to think about is this concept of appraisal. So caregivers often are uncertain about how they're doing and the caregiving role. And we often hear caregivers say, I just wish somebody would tell me that I'm doing this OK. And that would make me feel much better. So I think about this concept of support often, when I think about what caregivers need,

[00:16:45] **Caroline** Heather and Debbie each found their own way to give themselves a break.

[00:16:50] **Heather** I just made sure I always did something for me and tried to do something that wasn't hospital related. So when I was here, I ended up taking creative writing classes. So just something to kind of be a complete disconnect from the medical, the hospital, something that was creative, something that you use your brain in a different way, I think, than in a medical sense. And I thought that was really helpful and a good outlet.

[00:17:18] **Debbie** I did try to do what I could in terms of physically taking care of myself. Working out with a big stress relief for me, going to the gym. Fortunately, we have a gym in the building where I worked and I was able most days to carve out some time to go there during the day.

[00:17:41] **Jill** My father had a stroke when I was a young adult and my mother was his primary caregiver, so I had the opportunity to observe her as a caregiver to somebody in the context of our healthcare system, which I'll be honest, isn't very supportive of family members in the caregiving role. So I felt there was a big gap that I could address with my research. And then I went and started a Ph.D., which really started me down the road to do research in the area of family caregiving.

[00:18:13] **Caroline** Canada's population is aging. Dr. Cameron points out that the need for family caregivers is only going to increase. Our healthcare system's approach to caregiving has to change if we're going to be prepared.

[00:18:28] **Jill** So right now, our healthcare system is based on patient- or client-centered care. Officially, that does include the family, but in practicality it rarely does. So what I've been doing more recently is really trying to explore and understand how we can more formally involve and incorporate the family into the care of a person with a disability like a stroke. And if we can more formally involve them in care, maybe we can start to meet their needs as well as the person who has the disability. I'll give you an example. At one point in time, for a person to receive home care services from some of our community care organizations. For a person to receive home care services, it would be the patient that was asked about what services they would like to receive. And I remember a caregiver saying, You know, I really wish they had asked me as well, because he said no to some services that I would have really benefited from in my caregiving role. So unfortunately, home care services weren't traditionally allocated from a patient- and family-centered perspective. So the family's needs are not officially considered. So we need to rethink this because I think we could really help our caregiving population. We have to remember they are essential to the sustainability of our healthcare system.

[00:20:09] **Heather** In May of 2017, we finally got a call that a heart had become available for Jamie. He had been on the transplant list, then about just about a year. He went to surgery in May of 2017 and unfortunately there were many, many complications during that surgery, and he was brought out to the ICU, where he spent about three or four days. He never regained consciousness. We made the decision to turn off the machines as there was no real chance of a normal life due to some of the things that had happened during the O.R. So he passed away in May of 2017, just three or four days after his transplant.

[00:20:58] **Caroline** After six years, Heather's role as Jamie's caregiver had come to a premature end.

[00:21:06] **Heather** A friend of mine said to me after he passed, and you know, yes, you didn't have a long time, but the time you had with him, it was really special because it was just you and him. If he hadn't been sick, you would have been two people running around chasing career goals. Who knows, we might have had kids that, you know, all kinds of crazy schedules and that kind of thing. But the time you had was actually good quality time together.

[00:21:31] **Caroline** Quality time that allowed Heather to understand Jamie on a level nobody else could.

[00:21:38] **Heather** Towards the end of it, like, we could literally look at each other and know what the other person was thinking like. It just really kind of made us a cohesive unit and just so in sync and knowing that really we only had each other to rely on. I think it really made us very strong. Like two became one and we were very strong and could handle anything at that point in time.

[00:22:06] **Caroline** And through all the hardships, hospital visits and cheese grater moments, that strength helped to shape Heather's perspective.

[00:22:14] **Heather** There's a silver lining to everything, and I think when you're involved with someone with a chronic illness, what's the saying? Don't sweat the small stuff. A lot of those things that I think sometimes we get caught up in and we worry about really is not a big deal.

[00:22:33] **Caroline** Even after watching her mother change from the person she once knew, enduring the tearful drives and terrible winter weather and missing out on special occasions with family and friends, Debbie cherishes the time she cared for her aging parents.

[00:22:51] **Debbie** But I would say also, I looked at my caregiving years with my parents as my gift to them. This is something that I could do for them. That was in some ways giving back for all the years they had given to me. If I could help them to maintain their dignity and have the best quality of life they could under the circumstances. Then if I could do that, that was probably the most important part of my role. And I look back so often and those years, now, of course, I'm now almost five years past when my mother and my dad both passed away. I would say that's the one thing I feel best about. One of the things I feel best about in my life was that I was able to give that to them, and I would never take that back. I would never regret any of the years I gave to supporting them in their journey at the end of their lives.

[00:24:11] **Caroline** Thank you, Heather and Debbie, for sharing your beautiful stories of caring. And thank you, Dr. Cameron, for providing your expertise. Debbie said she was providing a gift to her parents. I believe caregivers like her are a gift. So often unrecognized in their roles, they serve their loved ones, their families, and ultimately reduce the strain on our healthcare system. It can be a really difficult job mentally, emotionally and physically, and they need support from family and friends, peers and professionals. Heart & Stroke believes in the power of community and provides information, as well as an online support group for caregivers. To learn more, visit heartandstroke.ca/connect. I hope you enjoyed this episode. Stay tuned for upcoming episodes on cardiac arrest, mental health and heart disease, and more. Thanks for listening to The Beat. And a special thanks to our donors for making this podcast possible. Subscribe now to stay informed, get inspired and rediscover hope. Don't forget to read and review the podcast so we can reach even more listeners. Stay tuned for our next episode! Until next time, I'm Caroline Lavallée.

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