



## Speaking from Experience *Cardiomyopathy/Heart Failure*

### Transcript for chapter 3 of 10: Changes in lifestyle

**Hylton, 69, & Eileen (10 years since Hylton's diagnosis):** I was battling with the fact that I was no longer invincible. And that was the biggest thing in my mind. The biggest thing in my mind was, "God, what's all this about? I'm mortal after all. I wonder how this is gonna affect the rest of my life."

**Alistair & Joan, 66 (13 years since Joan's diagnosis):** I was terrified. We had a grandson, at that stage, in Japan. And I kept thinking, you know, "Am I going to see him grow up? How long am I going to live for? Am I going to be bedridden? How's Alistair going to cope?" Because we are very close. We've been married 45 years. And I was initially concerned for him, as to how he was going to manage, because we're like one person. And if something's wrong with me, well, it affects Alistair. But, you know, after I got through... I have to say, it takes a long time, you know, before you even accept the diagnosis. And you go through such a range of emotions.

**Hylton & Eileen:** My confidence certainly took a big... took a big drop, you know.

**Hylton & Eileen:** Oh, it did, yeah. Because Hylton's work, he was travelling... He travels often. And he wouldn't go anywhere without me, in case... the fear of perhaps... he didn't... You know, he's in a hotel room and he didn't wake up or something.

**Hylton & Eileen:** For New York or London, she had to come.

**Kathryn, 41 (7 years since diagnosis):** I wasn't allowed to drive a car for six years after the original cardiac arrest. So that was a whole big deal to have to learn to live with. You just have to learn to catch the bus, take the kids on the bus. I actually ended up getting an electric bicycle, and that was a godsend, because it meant that I could duck down to the shops or, you know, do whatever without having to walk too far. Because I got very... well, still do get very tired and breathless when I'm walking. I'm OK on the flat, but going up hills is very hard. That's where the electric bicycle helped. I did things like get my grocery shopping on the internet and home-delivered because they would bring it in and put it on my bench. I didn't have to bend over or lift anything. Just... you have to learn not to be such a perfectionist about things like housework, because it's not important, you know. You do what you can, get other people to help.

**Kathy, 55 (2 years since diagnosis):** I chose not to go back to work as often as I was previously, mainly due to the fact that, if I was working, I couldn't put much time into the family, and I was finding it harder. So I'm still working but not as much. And it works well for me.

**Kathryn:** When this all happened, I was a stay-at-home mum, and the long-term plan was to get a job when the kids were at school. That was made a lot more difficult with my heart condition and just having no energy, being very tired. But I have managed to get part-time work... actually at the school where two of my children are, which is great. They're great, and



I just have to make sure I don't do anything too physical, that's all. That's probably my main restriction with working.

**Victor, 72 (18 years since diagnosis):** My work was a holiday. I was the best sales manager in Victoria. I used to travel to Sydney and Adelaide and Melbourne, with the furniture factory. And we were like family. And when I was crying, they were crying. They gave me a lot of support. I never worried about work. I could take as much time off as I wanted to, and still get paid. No questions asked. Because I have given the firm big, big dollars. So, even now, even after this, they wanted me back to work, but I can't do... When I can't do the job... as it should be done, I don't want a part of it. I want to do it properly and perfectly and... to be happy about it.

**Hylton & Eileen:** In my sort of job, you're either doing it or you're not doing it. I wish it wasn't true. I wish I could say, "Oh, I'll do 20% of that." But you can't. It's 100% or nothing. And, um... I think the other thing that I know now is, when I'm tired, I know to stop. Whereas, before, when I was tired, I might've pushed it on to the very limit.

**Jerome, 60 (13 years since diagnosis):** I quit smoking immediately. That was one of the first things that I did, which I thought was an absolute huge improvement for me in terms of the way I was feeling. Smoking really, uh... Smoking depresses all your body organs. The superficial smell outside your body is one thing. But what I've discovered is, in having been... 'Cause I was such a heavy smoker and I enjoyed it very, very much. But what I did find is that, um... that is what weighs down the health of your body. And I also gave up drinking alcohol. So that... and I do feel an improvement for all those... for that.

**Hylton & Eileen:** From the day it happened, I haven't had a sip of alcohol. And I wouldn't say that I was... I wasn't a boozier, but I was quite enthusiastic about, you know, whiskey and wine. I like them both. But when it happened, I thought, "Oh, I'm in a bit of a pickle here." And I talked to... there were three cardiologists on the job while I was... you know, at my lowest point. And the youngest guy... I can still remember him. He was a very impressive fellow. He's now working in America. He said to me... "Oh," he said, "normally, I'd say to heart patients, 'Have a drink. Have a glass of wine at night.'" In your case, good idea that you don't have any. Good idea." So, I mean that, from a social point of view... it doesn't make the socialising any easier. You know, if you're sitting there and everybody else has had, you know, the compulsory two or three glasses. But I'm a good driver after.

**Hylton & Eileen:** He's very popular, yeah, for driving. And he also has a wine cellar full of red wine, which is sitting there waiting for someone to drink it.

**Gaylynn, 62 (Had cardiomyopathy for 2 years; 8 years since heart transplant):** When I was first diagnosed with my illness I still had a lot of contacts at work. And I've kept up all my friendships. And so life has really gone on quite the same, except I wasn't feeling very well.

**Jerome:** I don't go swimming, or I won't dive into the ocean like I used to. And I'm very careful about where I go. I won't take stairs. They've got a program, how I'm going to get somewhere. So it's been a huge impact, because your mobility is reduced. Mobility we take for granted. Goes. It's gone. You know, it's reduced. But that doesn't mean that you can't enjoy life. I am enjoying my life. I'm enjoying my life immensely. But there's still that little thought at the back of my mind, "Wow, I wish I could do what I was doing. Oh, I'd love to be down at the gym now, pumping those weights." But, you know, I can't do that.



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**Kathy:** I've just had to come to terms with it, and... I realise that the professor at the hospital is the boss, and I just have to deal with it and accept it. And it hasn't been easy, but I do.