



## Speaking from Experience *Cardiomyopathy/Heart Failure*

### **Transcript for chapter 1 of 10: Cause & diagnosis**

**Kathryn, 41 (7 years since diagnosis):** Prior to my cardiomyopathy diagnosis, I was at home, a stay-at-home mum, with four children and one on the way. Keeping busy with all the committees and things, with school and Guides and Scouts.

**Jerome, 60 (13 years since diagnosis):** I was very active. I was training five days a week very intensely. I had a very busy social life – late nights, drinking, smoking – thinking that I was really enjoying myself a hell of a lot.

**Alistair & Joan, 66 (13 years since Joan's diagnosis):** You know, I exercised every day. I walked, which is how I actually realised I had a problem. I did water aerobics. I wasn't overweight. Really no reason to suspect that I had anything going on. But in hindsight now, I realised that I probably had had symptoms for quite some time.

**Hylton, 69, & Eileen (10 years since Hylton's diagnosis):** Well, the even that lead to my cardiomyopathy diagnosis was when I collapsed. And what do they call it? Sudden death or whatever it is. I'm told I died... when Eileen and I were out at a function one evening.

**Kathy, 55 (2 years since diagnosis):** It was a Saturday night, and I actually started vomiting. And, um... I had chest pain. And we were either going to call an ambulance or go to the local clinic. The local clinic could get us in within five minutes, so we went there. And, um... it was incorrectly diagnosed as gastro.

**Gaylynn, 62 (Had cardiomyopathy for 2 years; 8 years since heart transplant):** The GP that I had been going to really dismissed me... and thought that... that I was a public servant, and all public servant were complaining [Laughs]. And then the other GP that I went to, he specialised in sports medicine. And it was only that he had a new ECG, and he said, "Oh, perhaps I'll give you an ECG."

**Victor, 72 (18 years since diagnosis):** I came back from work one day and just took my coat off. And then I start playing basketball in my backyard. And I was better than Jordan. I was going... one metre off the ground and...and I was so angry and I was shouting out and all that. For 15 minutes... I didn't stop. And eventually, I went inside to change and, um... as I bent down to put my tracksuit on... something grabbed me here, like an octopus. And it wouldn't let go. I tried to... make different movements... jumping up and down... and I couldn't get rid of it. So, I called my wife... but I had the door closed because I was changing... and she couldn't hear me. And then I called her again, and again she couldn't hear me. And then I opened the door and I shout out. And my wife knows a lot about these things. And straight away, she said to me, "You're having a heart attack."

**Kathy:** I actually explained that I don't get gastro. And I actually, um... felt that it was a migraine, which is what he said it could have been as well. Felt that it was a migraine. And so I felt that the doctor was right, and so I soldiered on for the next six days, to the point



where I was collapsing, and got to the doctor, got an ambulance, got to the hospital. And I suffered a massive heart attack and aneurysm on the Saturday night.

**Alistair & Joan:** I went up to the shopping town and had the chest X-ray done. And, um... that night, I was telling Alistair that I'd had the chest X-ray and I must've moved because they called me back for another X-ray. And as I was saying that, the phone rang and it was our GP, saying he needed to see me first thing in the morning and that there was a problem with my heart. So I thought, "Well, you know, it's probably angina like Mum and Dad." So I wasn't overly frightened about it. But, you know, I thought, "Oh, well, go and see what he's got to say." So I went in the next morning and he had my X-rays up and he kept looking at them, saying... 'Cause I had been going to this doctor for over 30 years. And he kept saying, "I can't believe it. I can't believe it. I don't know how I've missed this."

**Jerome:** I started to develop a shortness of breath... quite severely... and did end up having some hospital visits as a result of the shortness of breath. What I was treated with at the time on my first experience, was tablets to make me pass water. And that seemed to relieve a lot of the pressure, and I thought I was back to normal.

**Kathryn:** It took a while for the diagnosis because they said things like, "This can happen while you're pregnant. It's not unusual to have palpitations." But after a few months, when it kept recurring every now and then and I had to go to hospital a couple of times to have the palpitations stopped, um... and then, by then, I'd seen a cardiologist and they said that I had hypertrophic cardiomyopathy.

**Alistair & Joan:** I was diagnosed six weeks before anyone actually told me I had cardiomyopathy. No-one said the word, that I had a heart problem. No-one said the word, that I had a heart problem. And I suppose because you're in shock. And I couldn't understand how... if you're reasonably fit, how could you suddenly have all these problems?

**Kathryn:** They've told me that it's just something I was born with, where no symptoms showed up till the age of 34, you know. But, um... that it's something I was born with.

**Alistair & Joan:** Diagnosis is critical. And in a lot of cases with cardiomyopathy, it's misdiagnosed in the first place. And some people are diagnosed initially with asthma, because of the... with the heart labouring and that have you.

**Alistair & Joan:** Breathing difficulties.

**Alistair & Joan:** Breathing difficulties. And the diagnosis, like most medical things, is critical.

**Jerome:** I let my, um... supervision of what was happening to me, I let that slip by... until I had another incident where I was raced to hospital... because, um... I couldn't breathe. So it really came from there.

**Kathryn:** It didn't mean anything, really, to me, much. It was just, "Oh, I've got this little bit of a heart problem." And I hopped on the internet and had a look and thought, "Oh, my goodness, people die of this. Oh, look, I haven't got that. I've got a mild version, obviously, and everything." I was on some medication... But I still managed to breastfeed the child, and everything was normal. Um...until... about 18 months after the first symptoms, I had a cardiac arrest while I was driving.



**Victor:** One third of my heart was burnt out and one artery was gone. So I only have two arteries and two thirds of my heart working. But the other people don't make it through, and I was very, very blessed and very lucky to get through... go through a very, very, very... severe heart attack.

**Kathryn:** I have no memory of it, of the event. I obviously passed out before I noticed anything happen, but I've been told that I crashed into the car in front of me. Some really nice passers-by called... they actually called 000 and the fire brigade came, because, you know, they thought the car might catch on fire. And they got there first. It was actually, um... the fire truck had a portable defibrillator, which was a new program at the time. And they did the defibrillation and resuscitation. And I woke up in hospital about three days later with a new defibrillator implanted.

**Hylton & Eileen** They said it was just a sp... it was a spasm. The whole electric of everything just... you know, just shut down. So they had to get that all stabilised and, um...and get him back again. So now he's living with a pacemaker and a defibrillator if everything stops.

**Gaylynn:** When I was diagnosed with cardiomyopathy, it came as a shock and I didn't know what to expect. At first, there wasn't a problem. But as the time went on, I deteriorated in health. But I know lots of other people that live with cardiomyopathy and have a normal life. Unfortunately, for me, I did need a heart transplant. But on the other hand, for me, it has been wonderful, because now I can have a normal life, and I'm very pleased about that.