



Speaking from Experience *Cardiomyopathy/Heart Failure*

Transcript for chapter 2 of 10: Surgery & defibrillators

Gaylynn, 62 (Had cardiomyopathy for 2 years; 8 years since heart transplant): You have to be assessed to go onto the transplant waiting list. And that's done through a series of tests and interviews. And once you become listed, then it's a matter of waiting till a suitable heart becomes available. And when you get that call, you have your operation. And, in my case, it was very good that I was able to leave the hospital within six days.

Kathy, 55 (2 years since diagnosis): When I was diagnosed as having a massive heart attack, I was in... trans... put into intensive care... and then transferred to a different hospital to have a... artificial heart implanted.

Victor, 72 (18 years since diagnosis): Doctor came. Doctor... my cardiologist. A wonderful person. And, um... she ask me how I feel. And she said to me, "Not to worry. Don't worry about anything. We will put a pacemaker and you're gonna live for a long time."

Kathy: The surgeon actually... once he operated, he removed part of the dead heart and got some supply to the back of the heart, and didn't need to put the artificial heart in, which was wonderful, a miracle.

Hylton, 69, & Eileen (10 years since Hylton's diagnosis): I worry about the pacemaker, you see, because my heart was bearing 45 times a minute before, so it's twice as... it's being used twice as often as it was before. That's probably absolute nonsense. As far as the defibrillator is concerned, they say to me, "Oh, well, if you ever have another event, this'd make sure that you didn't die on us." And so I'm happy about that.

Kathy: I have a defibrillator implanted. It hasn't discharged. I think in the first six months, it may have paced me, but it hasn't had any episodes in the last six months. It's on cruise control, apparently. [Chuckles] So...

Kathryn, 41 (7 years since diagnosis): When I have a fast heart rhythm, I can feel the little zaps that it might do to try and slow it down. It's just almost like a little tickle in your chest. But I have had a couple of the big shocks where I've been awake. It hurts very much but it's very, very fast. They say it's like a horse kicking you in the chest, but it feels like it's on the inside. But by the time you think, "Oh, gee, that hurts," it's over. Yeah, so... they liken it to pressing the reset button on a computer. So it sort of stops your heart and then it gets going again by itself.

Gaylynn: With the defibrillator, if it goes off, it gives you a shock, and you don't have very much warning. In my case, I didn't have very much warning. In fact the first time it went off was when I made the effort to go out to dinner, and I had the knife and fork in my hand and they went flying in the air.

Jerome, 60 (13 years since diagnosis): The, uh... defibrillator went off only one time. And I happened to be walking through my lounge room. The lights were out. I'd just got home from



being out. And my first experience was a big thud in my back. It's as if I'd been attacked in the house and someone punched me in the back. And the second immediate feeling I got is it moved up to my head. So I had been punched in the back and punched in the head. There was nobody there, and then I realised there must've been something wrong. So I immediately called the ambulance, finished up in hospital.

Victor: Once, we were coming back from a trip, and we stopped at, uh... Pound Road to let some people off. And we had jokes and laughter in the... in the... in the.. in the bus. All of a sudden, I was knocked FORWARD and BACKWARDS! And, for a moment, I didn't know what hit me, and where I was. But my wife was next to me and she realised what happened to me. And I said, "Anything happen to me?" She says, "Don't worry about it. It's OK. It's alright, it's alright, it's alright." I think... from that one, I found out that too much happiness and too much laughter... sometimes can hurt.

Kathryn: After having a large shock like that, I'm usually pretty tired, just not being able to breathe properly. You know, you worry that it's gonna happen again, or whether there's people around to help you if you need it. Usually, I would call an ambulance and they would come and probably give me some oxygen, and then go to the hospital or not go to the hospital, depending on how you feel.

Victor: When you have the defibrillator, you don't think about it. You don't think about something going wrong. And if it does... something goes wrong, there's something there to prevent it and give you peace of mind.

Kathryn: I think I was lucky, in a way, that I didn't have to decide to have the defibrillator implanted. It was just done for me because it was a life-threatening situation. Having it there is just so reassuring that it's gonna, you know, save me, bring me back to life, fix the bad rhythms, when it needs to. Yeah, it took a while to get used to. I'm still very self-conscious about the scar, because you can see it. But it's doing a good job, so you learn to live with it.

Having the defibrillator implanted was explained to me – "It's an insurance policy." And that's how I look at it. It's an insurance policy. Should I ever go into cardiac arrest again, it will save me. So it's a great comfort to have it.