Speaking from Experience
Cardiomyopathy/Heart Failure

Transcript for chapter 8 of 10: Support

Victor, 72 (18 years since diagnosis): I had the support of my family and always encouragement. They were by my side no matter what happened. And they were living... the life I was living WITH me. And they were full of encouragement and... and love and affection, which... That's what you need.

Kathryn, 41 (7 years since diagnosis): They were really good, especially when I wasn't driving. My husband would just spend the whole weekend driving everybody everywhere – and driving me to the shops and helping with all the shopping and everything. The kids, yeah, had to put up with me not being able to do lots of the things that other mums could do. It's not so bad now. I'm pretty good. But in all of that, the kids did learn to be very independent – to catch public transport everywhere and get themselves around, which was one benefit. My mum and dad, everybody worrying about me, looking after me. Which sometimes gets a bit annoying too, because you wanna do things and people say, "Oh, are you really sure you should?" But really, having a family behind you, having a local community... One of the children was in kinder when it all happened. They organised rosters to pick up the kids for kinder and school. The church group sent home meals, you know... I don't know how people would do it if they're very isolated, but you need to learn to accept help from the community around you.

Kathy, 55 (2 years since diagnosis): When I first came home from hospital, I had some neighbours that would always drop off a meal, which is wonderful. I've still got a neighbour who comes and gives me a meal every week, which is just wonderful – that two years on, she still considers doing that. And it's lovely to have that support.

Gaylynn, 62 (Had cardiomyopathy for 2 years; 8 years since heart transplant): Well the most important thing is just knowing that your family and friends are there for you and if you call them, they've got time for you. Everyone has a busy life, and you do find that it's really your closest family that is your support. But it's still nice to be able to keep up all your social contacts. And that's what I did. I just made sure that I telephoned people and they would call around and see me when they could. So I was very lucky.

Kathryn: I had a psychiatrist visit me. It was not early on. It was after about... probably a year. And... A year after the cardiac arrest. And I just was feeling, "I'm not coping well with this." And I felt a bit silly getting a psychiatrist to come, but they came from the hospital, she came to my house. It was easy. It was just someone to talk to. I felt silly because I wasn't doing anything more than talking and she wasn't really doing anything more than listening. But it gave me someone to talk to and to vent some of my frustrations without worrying my family even more. So that was really helpful. There's lots of help out there. You've just got to find it and use it.

Alistair & Joan, 66 (13 years since Joan's diagnosis): People with cardiomyopathy can become a bit isolated and have no-one to share it with, so that's you know... You can't organise these things. That's the way life is. But it's... Certainly the support of other people with similar problems is critical. And then they can, as we say, "care and share".

Kathryn: Early on, when I was diagnosed... I actually joined the Cardiomyopathy Association of Australia support group, and I found that very helpful. Very helpful socially and mentally-wise, just to talk to people who were going through similar problems. But they also had lots of practical suggestions. They gave out a list at one stage of how to do things... You might not think that you can do your ironing sitting down, but you can! And practical suggestions like that to help someone who doesn't have a lot of energy to do things.

Gaylynn: The Cardiomyopathy Association has had an important role in my journey. Since first going along and being welcomed, I've always felt that I've had that support. And it's a wonderful feeling to know that there are people there that care about you and your condition. And that's why I still like to belong to the association. And I recommend that anyone who's thinking about joining should join.

Hylton, 69, & Eileen (10 years since Hylton's diagnosis): A little bit more care can be given to the carer and the family. And I think I would encourage anybody to make contact and... and just see how things are going. Maybe even take over one of the hospital visits or something like that. You know, it all helps.

Alistair & Joan: I think the carer needs as much support as the sufferer. So please, please, think of the carer. Think what they're going through. And hopefully they're getting help and they're getting support, because it's so important.