



## Speaking from Experience *Cardiomyopathy/Heart Failure*

### Transcript for chapter 4 of 10: Your health care team

**Hylton, 69, & Eileen (10 years since Hylton's diagnosis):** The GP I go to, uh... In an era when... where GPs perhaps are not as revered as they were, you know, 50 years ago... the GP I go to is fantastic. He knows me well. He knows exactly what I... He knows exactly what he's got to do to get me into his waiting room. And between he and Eileen... Just little things, like I can't ring up the chemist... I can't ring up... I can't ring up the GP for a repeat prescription. The rule is, I've got to go and see him. Which was something that Eileen... I think Eileen took... That was her initiative, but he just said, "Yes, that's what we'll do." So that's a little thing that makes me go to him. And, um... if I haven't been to him, say, in six weeks, he'll want to know why. So I think that I've got a terrific relationship with my GP. I get on well with him – he's a younger fellow. He and I get on well.

**Gaylynn, 62 (Had cardiomyopathy for 2 years; 8 years since heart transplant):** I made inquiries and was recommended to a particular GP. I telephoned the clinic and asked if she would be interested in taking me on. And not too long later, she phoned me back and had a chat with me, which I thought was very good. And I've been extremely happy with my GP ever since then.

**Jerome, 60 (13 years since diagnosis):** It's good not to be a number, like a customer at a bank. So the relationship between your medical practitioner and yourself, very important that it's, um... doesn't have too much of a distance between it. There needs to be some... small social feeling about meeting with your doctor.

**Alistair & Joan, 66 (13 years since Joan's diagnosis):** A lot of cardiologist are not specialised in...

**Alistair & Joan:** Cardiomyopathy.

**Alistair & Joan:** ...cardiomyopathy. And so that can be very useful if they, you know, have a particular stream, that they're interested in, in cardiomyopathy. So... I think if you're uncomfortable, then you perhaps need to review it. And, in some cases, we've found that, um... in talking to other people with cardiomyopathy, that they, um... they actually go to the hospital... one of the hospitals... the major hospitals that deal with heart... have a particular cardiac unit. And then they get another stream of referral where it's appropriate.

**Victor, 72 (18 years since diagnosis):** Of course, the most important person is you. You have to tell the doctor the truth – how exactly you feel, and then the doctor will do what the doctor thinks is right for you. 'Cause everybody has different needs and different expectations.

**Alistair & Joan:** Well, you learn how to...

**Alistair & Joan:** Advocate, yeah.



**Alistair & Joan:** Yes. Yes, yeah. And you know how to talk and what not to put up with and how to demand answers.

**Jerome, 60 (13 years since diagnosis):** But I find generally, the medical profession, of all the experience that I've had, they are a caring lot. I haven't met one that doesn't care or that I've felt doesn't care.

**Kathy, 55 (2 years since diagnosis):** The health care team that I am dealing with is fantastic in the sense that there's a social worker there available for you, there is the dietician, there's heart failure nurses, there's the cardio... There's registrars, if you don't have a major problem, to check you at any time that you need to be checked. Or if your echocardiographs have to be done and there's a professor there. So all your questions are answered in the one day, in the one unit, which is fantastic.

**Alistair & Joan:** And also they need to find a good rehabilitation program, because they'll get a lot of knowledge and a lot of help and a lot of support and that's really, really important.