



Speaking from Experience *Cardiomyopathy/Heart Failure*

Transcript for chapter 10 of 10: Words of wisdom

Alistair & Joan, 66 (13 years since Joan's diagnosis): For someone who is just recently diagnosed, I would say get as much information as you can, and try and get... live with the support that you can get. Recognise what support is available, be it the cardiac units of the hospital, or cardiac nurses, or social workers, particularly with your GP. And through that and through your cardiologist, understanding what's going on with your body, and, as in most cases with a chronic illness, the better informed you are, the better equipped you are to deal with it. So hopefully you can then relax and then get on with... with what you... with... treatment, in the knowledge that you're going to actually improve your lifestyle, which is the critical thing. If it's possible for you to do exercise and improve your own status, then that's the way to go.

Jerome, 60 (13 since diagnosis): Your body and your mind is all you've got. People say they've got a house, they've got a car and they've got... No, I don't think they've got anything. What you've really got is your body and your mind. So if you look after that, well, everything else comes easy. But without the physical capacity and the health capacity to participate in whatever it takes to do to have what you want, or to be who you want to be, it won't happen if you can't stay in good health.

Alistair & Joan: If I ever found myself short of breath, the first thing you would do is ring an ambulance, because you need to be assessed, and the ambulance people can then... They'll be the ones that assess whether or not you need to go to hospital. And I think that's very important.

Kathryn, 41 (7 years since diagnosis): Take advantage of all the support services available at the hospital if you've been diagnosed in a hospital – things like the dietician, the physiotherapist, the exercise programs, even the psychiatrist.

Gaylynn, 62 (Had cardiomyopathy for 2 years; 8 years since heart transplant): It's very important to be in a support group. It's like any other peer group. You just need someone to talk to who really understands what you're going through and you can relate to. And it's a wonderful way of meeting new friends. Since I've had my illness, I now have a whole new lot of friends. It's great.

Alistair & Joan: You've got to understand that there are ups and downs. And so some, uh, empathy with that is important. It's just a question of normal life, I guess. You deal with ups and downs and give support wherever possible.

Hylton, 69, & Eileen (10 years since Hylton's diagnosis): Get your confidence back quickly, and make sure you've got somebody beside you who can help you. That'd be the... They're the key things.



Kathy, 55 (2 years since diagnosis): I would say “It’s not the end of the world”. Look at where I was – considering where I was to where I am now, what I’ve been through, and I’m leading a normal, healthy, fulfilling life... just a little slow.

Kathryn: You just take one day at a time, do what you can do and pass on the things you can’t do. You know, you’ve got to learn that you can’t do everything. Even though you try [Laughs].

Victor, 72 (18 years since diagnosis): You’ve got to think positive. And speak your mind. No use bottling things in and... You’ll probably get another side effect. Speak your mind, and do the best you can under the circumstances.

Hylton & Eileen: It’s a big hurdle mentally for a sufferer to cope with – to know that the most important part of your body, the most important muscle in your body, is not functioning properly. And to believe that it can be assisted by mechanical means, you know, is something that a sufferer has to cope with also, mentally. And I just think that, you know, you just... If you’ve got the patience and your lifestyle is good, your relationship is good, well, I can’t see that there’s any problem. Just look forward to a long, extended life together. As much as you can.

Hylton & Eileen: Good on ya.