



Speaking from Experience

Chronic Obstructive Pulmonary Disease (COPD)

Transcript for chapter 10 of 11: Support

Chris and Reg, 83: I think the support of a family in a situation like ours is vital. They might not be able to do practical help, although they can, as well, but just the, emotional support, the phone calls. And if there's an outing, we're going out together, they prepare, they find out the way to make it easy for us.

Graham, 69: My wife and friends have been very supportive to my condition. They realize my limitations. But they also push me a bit. Like, for example, "You haven't mowed the lawns yet. You don't have to do it all today. You can do the front today and the back tomorrow." So in that way, they're supporting me. They're pushing me to do, and not sit on my backside all the time.

Ruth, 72: I do live at home alone. But I have a great system in place.

Roy, 53: The day I gave up, my wife had had a couple of cigarettes, and she said, "Alright, we give up," and that was the first thing. If she was still smoking in the household, there's no way I the wide world I could have given up. I didn't ask her to, but she committed to it. She said, "Oh well, we've given up." Since then, it's "What are WE gonna do about it?" Initially, as I said earlier, my two kids were involved in some of the running events that we entered, like fun run. But they're got a social network now. There's a computer. They've moved on. So the wife keeps saying, "We're going for a run." Not "you are" or "I am." "We are."

Ruth, 72: I have somebody else, a very old friend of more than 50 years, whom I call 'the galloping gourmet'. She cooks for herself and her husband, and adds on for the child and freezes it, and comes over every week or two with a basket full of frozen food. So I'm enormously lucky. I have a son who shops for me, who gets my pharmaceuticals, who is at my back and call to take me to the hospitals and anywhere I have to go.

Colette, 45: I have a fantastic job, a fantastic, understanding boss, a partner who just adores me, family who support me, friends who support me, my life is just... I'm in one of those happy bubbles.

Chris and Reg, 83: I've always been deeply involved with everything that Reg does and with everything that Reg goes through.

Chris and Reg, 83: We work as a team pretty well.

Chris and Reg, 83: And so we do most of the time. So I've always attended everything, and learnt as well. And this is a great help, because then I understand more. I understand more of what he's going through. It's very hard to understand what it's like. Even though I've lived with Reg all these years, it's still hard to realize what it's like not to be able to breathe.

Julie, 58: It's hard for people to understand that, but once, when you talk to another COPD, survivor [Chuckles], there's a knowing.



Chris and Reg, 83: Support groups are... to me, have been the source of learning management skills and management skills are important, because if we know what's going on inside, we can manage ourselves better. And support groups, we hear speakers, health professionals come and give us talks about medication. At our last support group meeting we had a senior lung function scientist, come and talk to us all about oxygen, what it means to a respiratory patient. That was very helpful.

Graham, 69: We have a little exercise for half an hour, which is walking, lifting light weights, then after, a little bit of a social get-together with a biscuit and a cup of coffee or tea, and we talk to each other about our problems and that's very helpful.

Ruth, 72: If you've done a pulmonary rehab program, you will find, in conjunction with that program, they give you a coordinator – a physio that's a coordinator, who in turn is able to supply, another physio, the district nurse, psychologist, OT person – everything that pertains to your health and the safe management of the environment of your home. Even apart from your family or partner, children, these are the medical people that are put into place. And you have their telephone and you can ring them at any time, and they're just wonderful.

Christ & Reg, 83: Having found a good GP doctor, it's important to develop a good relationship. I've been seeing my bloke for over 20 years now. And we're on a first-name basis. And I go to him with a little shopping list, and it might be a report for a blood test, or reports from a lung function test, or something I read in the paper, to ask him about. And it's got so now sometimes he'll say when I go in, "What's on the list today, Reg?" I see our relationship as a team effort.

Ruth, 72: It's really important that you have a rapport with your doctor, that you are able to ask them questions. And if a doctor that you're going to... Not that they're so reluctant to tell you, it just they're all... they all have different styles of communicating. Then you need to change. You need to change and go to someone with whom you have a lot of comfort and can feel comfortable asking questions.

Chris & Reg, 83: The personalities are so important. Whilst some of our doctors aren't very good communicators, some of our patients are not communicating very well either. So, the patient has got to play their part. And Christine and I had a holiday in the Barossa Valley, and I picked up a couple of bottles of wine for my doctor, because I'd heard he was... he liked a taste. And I told one of the support group what I'd done and he said, "Ah, bribery eh?"

Chris & Reg, 83: Not bribery. No.

Chris & Reg, 83: And I nodded. I said, "Yes!"

Chris & Reg, 83: No!

Chris & Reg, 83: [Laughs]