



Speaking from Experience *Stroke in Midlife*

Transcript for chapter 5 of 9: Rehabilitation to independence

Helen, 54 years, stroke 11 years ago: The opportunity to have therapy is just so important and significant and it needs to be on a daily basis. Day after day, week after week, month after month, and now I've found year after year.

Leonie, 37 years, stroke 4 years ago & husband George: I had to mainly do three things. One was to be speech pathology, occupational therapy and physiotherapy.

Noelene, 63 years, stroke 7 years ago: I had to learn to speak again. I had the help of lovely speech therapists, and they helped me.

Jack, 53 years, stroke 11 years ago: I did a lot of exercises which I thought were silly but when I think back, they were needed. They knew what they were doing, I didn't.

Leonie & George: The speech pathology, I think, was probably the most important thing in my mind, because I had such a terrible speech problem, that I was unable to say so much, that I needed to relearn.

Robyn, 48 years, stroke 11 years ago, & mother Cath: Physiotherapist, as soon as she saw her...

Robyn & mother Cath: Wonderful.

Robyn & mother Cath: ...she said, "Away with the chair, you're going to walk". At that stage she could walk, just. And they'd sent her walking around the block eventually, much to all our horrors.

Robyn & mother Cath: [Laughs]

Robyn & mother Cath: She walked right around the block, which was a huge block. But she had to do it, and she did it.

Helen: The occupational therapy, more on your day-to-day living skills, it's a lot of just over and over and over again, practicing and trying to do things. Trying to hold a pair of scissors in your hand. Trying to hold a pencil in your hand. Trying to hold your toothbrush in your hand; those sorts of things. Trying to comb your hair. Trying to bathe yourself; those sorts of things. And then in the physiotherapy, trying to get the arm to work again, trying to get the leg to work again. Trying to get those movements. To enable you to walk again. But you really are back to square... And I suppose that in some ways, you are a baby again. You seem to regress so much and you just have to relearn it all.

Noelene: From being independent to being dependent on others, and that was hard.

Leonie & George: The stroke, I think within the first week of having the stroke, I think I lost 7 kilos and my muscle waste, my muscles were wasting away. So I had to do that straight away, and that was great.

Leonie & George: It was also retraining yourself how to walk and how to use her right arm. Speech therapy was not only just talking, we have to remember that was teaching her how to read. She was relearning how to write again. It was really re-educating herself how to do what we just expect from the average person in life.

Noelene: At first it was hard to adapt, but I received so much help and assistance there that I'm forever grateful.

Helen: When you're in hospital for such a lengthy time, you just wish for the day when you can go home. I mean, like a lot of things you wish you can do. But in the hospital there's a security. There are people there who are actively involved in your rehabilitation, and getting you well and getting you walking again; getting you to learn to dress, to feed yourself. All these things, there is a security about that. But all this time, you're wanting to go home. After a period of time I was able to go home for weekend leave and I can remember on a Sunday afternoon about three o'clock, that deep feeling of 'Oh, I've got to go back.' But I used to tell myself, "I've got to go back so I can come home and stay at home".

Robyn & mother Cath: I've tried to hold back. It's often much easier, when you see her struggling with a plastic bag in the supermarket with one hand, you have to hold yourself back not to help. I've tried very hard to let her do it, because she wants to and she's got to learn, I think. Would you agree, Robyn? How do you feel?

Robyn & mother Cath: Yes, I mean walking down the street and to the supermarket and back again...

Robyn & mother Cath: You want to, don't you?

Robyn & mother Cath: It's tiring, but yeah.

Robyn & mother Cath: You don't want people helping you all the time.

Robyn & mother Cath: No, I mean mum, yeah, but learning to be sufficient.

Robyn & mother Cath: That's right, yes. And it gives you the confidence too.

Robyn & mother Cath: Tiring, very tiring.

Helen: I was able to buy another home unit and I manage extremely well. I have that extremely well set up. From a water-operated lift to get my wheelchair up on the decking. I can manage stairs, as long as I've got rails on either side and I've got a few stairs outside out the front. I've got the bathroom set up exactly with rails and stools so that I can get in and out of the shower by myself. I need help in the home on a regular, weekly turn-about. I need help with my shopping and my banking and those sorts of things. But I have a terrific network of people from family and friends enable me to live independently. But I wouldn't be able to do it unless I had those supports.

Robyn & mother Cath: I live on my own.

Robyn & mother Cath: That's right. And loves it, don't you?



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Robyn & mother Cath: Lovely. Really lovely. I mean, I'm on my own, wonderful. I mean, surroundings... situations, lovely. Just lovely. Really wonderful