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Speaking from Experience
Motor Neurone Disease

Transcript for chapter 3 of 8: Concerns

Jackie, 12 years after diagnosis: Because I was in America with an American husband, I was wondering how I was going to cope, seeing as my immediate family wasn't around me.

Peter (1 year after diagnosis) and Joanne: My biggest concern would be my kids and not maybe seeing them.

Jackie, 12 years after diagnosis: One of the worst things was having to give up nursing. That was a big thing, because even though my mother is a nurse and I didn't want to be following in her footsteps, I felt that was something that I could do and do well.

Peter (1 year after diagnosis) and Joanne: Sport was, it used to rule my life, I suppose. I love it, playing. That's probably the most frustrating thing I'm facing now. Mainly the bridge where I was ok, 12 months ago, the time in between when you know you couldn't do, to finally saying, enough is enough. That was probably the hardest thing.

Des (6 months after diagnosis) and Wendy: We felt it was appropriate to tell the more immediate members of the family and we've each had our ration of those people to tell.

Peter (1 year after diagnosis) and Joanne: I suppose it's a conversation killer when you tell someone something like that. So, go along with the flow and if it comes out, I'm happy to talk about it. But I don't think it's fair on them to hit them with something like that.

George (4 years after diagnosis) and Gerda: A lot of people, when you say 'MND' nobody knows. It's not a very common sickness.

Margaret (Peter's mother): I just told anybody that I know. I mean, there's no point in pretending it's not happening.