

### Transcript Carole Parkinson's Disease

That was really how I really got involved with any professional body, any any organisation or anything, and from there, they asked me to do teaching sessions, with professionals, to talk about being a carer, not about Parkinsons, it was a generic carer, so erm I went along, I think it was every two months that I did a session with social workers, um, social worker students, therapists, er, community nurses, and just told them what it was really like living with a chronic illness, and then I got onto the steering group at the carers project, steering committee, and I oversaw what was going on in the carers project, and then

(pause) we had a lot of problems at home, with housing, neighbours, all because of Vic's illness, no one understood that he was really ill, and I was really at rock bottom, and I rang a branch of the Parkinsons and and I said, you know, I need help, these are the problems that I've got, and to be honest, no one knew what to do, it it was so difficult to deal with and it was, they'd never had the problems before, they hadn't had erm people being, being erm, housing problems where you were going to be moved out of your house, or, or erm, not being told it was early stage Parkinsons, they said didn't understand what was going on, (coughs) and so I thought well if I can't change it from the outside, I need to change it from the inside so I went along before Vic died, because John and I, I went along to the erm local branch, and I started to get a little bit more involved, got a little bit more information, Vic didn't want to know, he didn't want to go, he couldn't go really, he was too ill, and I used to go every month, and they needed a secretary, so I had me secretarial skills, so I thought well I'm here, I can do that, and give me something for me, and I became secretary, and, and then I think it just progressed to be honest, I didn't, it was no planning on my half, it was just someone saw that I had lots of erm information about Parkinsons, lots of experience, so the local people decided that would I like to be chair, so I thought well, ok, I'll become chair, so, and I ran the local branch for about a year and a half, and in the meantime I was asked to do teaching for Northumbria university, for professionals on being a carer for the chronically sick again, and erm, I was asked to sit in on, um, panels for um caring, for social services, I can't remember, the list is endless, but I (interviewer: unclear)...yes, that's right, I did, I did everything, the EMB, cos I did the EMB course, and I would I would erm, I would sit in, sorry I would do a teaching session and that, it started off an hour, and then they give me a full afternoon, and then they erm, they asked me to erm, read the abstracts and listen to their presentations and help to, to present the prizes. So that was really, such a boost, er, Vic was around at first, when we first started, erm and he did enjoy that, you know he didn't say very much, he was there centre of attention, and then I continued when he died because it was relevant (unclear) for the patient, but it kind of encompassed us both, and, um, and then just out of the blue there was a position in national office, and it was on the their board of trustees, and someone said go for it, and and I said well I'll never get on because they, it was always classed as an 'old boy' network, very erm upper middle class, very well-to-do, and some of them don't have Parkinsons and I thought well, they won't want me, but ok, I'll go for it, so it was kind of like for a bet, I bet I won't get on, I bet you will, ok I'll do it, and, um, I was voted on. Er, and, er, by a quite high number of people, and I think it was everyone who has Parkinsons who sort of lived, or or or, not everyone in the North East, I have to say, but a lot of people in the North East thought because I was (unclear) and I was one of them that it would, that was why I think I was just, em, (unclear) put on the Board. And I went to the Board, I have to say I was really worried, I was very scared, erm

because I've sat on panels before, but I'd always had ground rules where.. they're very highly educated people, and usually or they're consultants, other professors.