

I Ok, well thank you very much for agreeing to take part in these interviews. What I would just like to ask you is if you could just reflect on your Parkinson's, how it started, how it affects you and particularly about your medication and particularly your experiences of taking medication in hospitals

F Right, well I was diagnosed in 1997 but looking back now I can see that I had symptoms a lot earlier than that, but it was the people I worked with who realised that I wasn't using my left side and I did become quite ill at the end of that term and I was referred to a neurologist which was a surprise to me and very worrying. And I, in a sense I was relieved when I did go to see the neurologist and he told me that he was almost 100% sure it was Parkinson's and I had suspected things much worse so in a sense I felt a bit of relief. And he said to me at the time I can't cure you but I can help you manage it. And so I thought 'that's fine for me' and I hoped that I would get settled on some medication and then just be able to take up my job again.

It didn't quite work out like that. The first medication I was given was Benhexol and we went on holiday to Switzerland and really that was a very difficult time because the drug didn't agree with me and I was having dreadful muscle spasms as well as feeling very, very weak and in fact we had to go to the doctors in Switzerland and he rang through to my doctor in England and I was told then just to stop taking that drug. And after that, because the consultant then put me on to Sinamed and Ropinarol and they're the main drugs that I've had and I've been taking them ever since. And the dosage hasn't gone up very much. Along the line, we added it in 2001, Chlopinamine and that's to take at night time and that was to help with this disturbed sleep patterns and also I was having tendency to be obsessed about doing jobs perhaps at an inappropriate time. And that certainly has helped and so I'm still taking the Chlopinamine at night time and then the other addition I'd say about five years possibly, was the Amantadine because as time's gone on, the dyskinesia has become more of a nuisance and I find the Amantadine does help so that's my stock collection of drugs that I take. And I've managed with them pretty well.

A few years ago I did have a problem with a rapid heartbeat and problems with my blood pressure falling when I stood up and I was sent to hospital. My own doctor sent me for, and the conclusion of that really was that it was side effects from the tablets so again we were back to management and things come and go. For instance when I go to my yoga class, I've got to be careful about standing, getting up too quickly but in general I manage with them pretty well and the main thing about the Parkinson's for me is the overwhelming fatigue. I feel as if every day I have a mountain to climb, that little things take this extra effort all the time, but I have had excellent care and wonderful resources.

For instance I've just finished a month doing the speech programme which has been a great help to me and I go to conductive education which is now well established in the North East and that has made a great deal of difference to me. So -I can't speak too highly of the care that is on offer and that I've had benefit from.

I How important is the medication to you in terms of managing your Parkinson's?

F Well it's very important because I am totally dependent on the medication. I am fortunate in that I don't really experience suddenly going 'off' or bouts of freezing. I can recognise when I'm due for some tablets, I describe it as 'I feel I'm going down the slide' and I then would take some and would have a pretty quick reaction and start to feel more myself again. Recently I did ask if I could take an extra tablet in the evening, I started going to a singing

evening class and I find at the moment I'm going from about five o'clock in the evening until the next morning without any medication and when I'm out in the evening, I do feel the need for a bit of a boost so I have that option now of increasing the tablets to four a day if I need to.

I Ok, can you reflect on any experience of medication when you're in hospital? Is there any issues there?

F Well the only time that I have been in the hospital is that time when I had the rapid heartbeat and I was sent down to the casualty and I was given opportunity to take my own tablets just when I wanted. But I didn't stay in the hospital so I can't really say much about ... that was the only time

I So you were able to manage your own medication?

F Yes and the medical staff were quite happy for me to do that

I Ok

F Yes

I Excellent. Is there any other reflections, thoughts you want to contribute to this? About your Parkinson's and medication?

F I think that having the medication that suits me and taking it at the times that I have said, has meant that I, that there's a lot of things that I can still do. I am very fortunate to have my mobility and I really prize that. And I do recognise with it, that without the tablets I can't imagine really how I would be. I don't think I would be able to attempt half the things that I do so again I'm very grateful for the medication I have and for the help that they give me when I go for reviews and the involvement in my own treatment. I think that that makes it easier and makes you feel still a bit in control.

I Ok, well thank you. That's brilliant. Thank you so much.

F You're welcome.