

I go to work, I socialise a lot, I try to have as normal a life as possible. I pursue all the interests that I had over the years and Parkinson's has never really stopped me doing anything. It's just that I've had to think of ways to enable me to do things rather than not doing anything at all. I still go horse riding when I can, but I have to go on a known, slow horse. I still ride my bike a lot; I have to just allow more time to get myself ready for these things. I travel a lot; I go away and see friends and so on.

But I just have to plan things out and that's really what it's meant in my life that I have to be a bit sort of over enthusiastic on the planning stages and get everything off to a T then things are fine. But I like doing that anyway so that's fine. Basically I think what I'm saying is that Parkinson's has never been the focus of my life; doing what I want to do and following my interests and following the boys and things like that have been the focus. Parkinson's has had to fit in with that and I think that that's perhaps the whole approach to the illness or the condition that I have is that I try to put it to the back of my mind and live life to the full.

My, the teams that have been involved with me have always helped me with that and suggested all sorts of things and ways of coping. My physios have told me about mirroring and what to do when I freeze and queuing and all this sort of thing which has been really helpful and exercise and following through; stretching exercises as often as possible and that's really helped me moving and does help me a great deal.

I also take a lot of medication that has gradually built up from being very little medication to a lot of medication that I now take on a three hourly regime throughout the day. But I've been taught by the PD nurse and the other members of the team how to take it on time and to keep as long as possible moving and functioning normally. I'm not aware of looking any different or moving any differently when I'm on a good day; on a bad day I shake a lot but I can always do what I plan to do. Whenever I've had a problem and thought 'right this is it, I'm going to have to change my lifestyle' or whatever, my consultant and the team have always come up with a way round things that, either by altering medication or exercise or whatever so I have a great deal of faith in them. Changing the cocktail of the medication has helped in that I find that as long as I stick exactly to it, on the times, that you know generally I'm fine.

There's been some problems when I've been in hospital and most of the time I've been in hospital for problems with my Parkinson's so I've been on a neuro ward and when I've been in a neuro ward there's been problems in getting my medication on time which I found really quite strange on a ward where there are meant to be experts in caring for people with Parkinson's, but it's surprising how little training or understanding that there is or was done in Parkinson's.

More recently I've had a lot of input from social services and the health team who have together come up with a direct payments package where I buy in care, where I buy in care that I need when I feel I need it and that has worked a lot better than me being admitted to a neuro ward. I'm not being critical of the individual members of staff who have been available to me on the ward, they've all been very kind and professional people but they haven't had intense training in Parkinson's and how you MUST have your medication on time and when I don't have it on time I go off and become really uncomfortable. And I've felt as though I've been a nuisance sometimes and I've had to ring again and say 'you know I really do need my medication' and so now when I go into hospital which I haven't been to a neuro ward for over two years now since I've had the direct payments to buy in my care

when I need it, I find that the staff are a lot better trained and know and understand why you need to self medicate or have your medication on time.

Self medication has been on the option on the couple of occasions when I've been to hospital and that works very well for me but I do understand the problems on the ward when there's patients may have access to your medication, you've got to be very careful. So you lock it away all the time and so on, and you are responsible so I do understand the problems with implementing the schemes, the self medication but I think that the direct payment scheme has helped keep me out of hospital because I can ring up and get care and support whenever I need it and not on a routine basis, so that's what I do and it works well for me.

I have a worker that I know, whom I'm pleased and comfortable to have in my home, she knows me very well, she knows exactly what to do when I'm feeling quite poorly and because of her we've been able to nip things in the bud. I just ring for her to come in and she comes and sorts me out and then goes and I get on with life for another few weeks. So it's, that's really helpful.

But recently I had an episode in hospital for something that wasn't associated with my Parkinson's and I asked whether I could self medicate when I first went in and I was really surprised when I was told that 'yes I could do' and they were very supportive, they were great on the general surgical ward and I was, there was no problems at all, those first days that I went in but then I unfortunately had complications and wasn't able to self medicate because I was in the high dependency unit and had, had to have a transfusion and had drips and all sorts of things plus other medication and my Parkinson's couldn't be kept under control for a while 'cos it couldn't be given intravenously and I did definitely have real problems because I kept moving and became restless and so on and I had to be given medication that was not my usual medication and I had to take a (inaudible) that's dispersible rather than the usual medication cocktail that I take and so I did become quite uncomfortable and so on until they refined the Parkinson's medication. But the hospital team worked very closely with the PD nurse and my consultant neurologist and they were able to really help me so I was very lucky that there was such supportive staff who would listen to what I was saying or needed or what was uncomfortable and together we worked out a solution to it but that was only because of the interest of the staff who were nursing and their support.

But I think it's very important where possible for people who have Parkinson's Disease to self medicate when they are in hospital; it means that there's less pressure on the staff and that the patient can regulate how they're feeling and keep on top of it and keep them self comfortable. A lot of the time I've seen people with Parkinson's on the wards who've not been listened to, not purposely ignored but people don't realise because they're softly spoken or their voice is weak then they don't hear necessarily what somebody's trying to say to them. So I think I would just encourage people to listen as much as they can to people with Parkinson's who usually know their own condition, the way they're the feeling best and to go along with that wherever they can.

I think that's why as I say every individual that I've come across has always wanted to know more and to talk about it and to try and communicate what their needs are and so that's what I always try to do. Sometimes people think that you're being stroppy but it's not, it's trying to work out a solution that will work within the ward as well. My time in a hospital has always been very positive, all of the staff that I've ever been involved with me have been

really wanting to find a solution for whatever problem I've had and I think as, as long as I can I'll try and develop good relationships with them, because I've never come across anybody who hasn't try to do their best for me or tried to work things out with me.

I think it's really important for people with Parkinson's to help themselves as well. I've found that people with Parkinson's seem to be hesitant in coming forward and being assertive and saying what they're wanting and following that through and that's sometimes created a problem for themselves. I always believe in trying to communicate with people even if it's difficult and difficult sometimes in terms of energy as well to actually sit down when you're feeling dreadful and trying to put in your wishes or what you want to have done in to words is really difficult sometimes when you're feeling poorly or off. But it's so important to communicate and I think that we've all got to take responsibility to doing and I would just ask that professionals listen to what we say and I've always found that they have done and I think that's basically my story so far.

I've got a deep brain stimulator that's fitted, I had one put in at about ten years ago and then one was put in about five or six years ago and that's helped me a great deal to keep my mobility and the staff that I came across on both occasions worked tirelessly to get the brain stimulator working correctly and I just found everybody so helpful and just little tips that the staff were able to give me helped me so much in life's, when you're at home and out and about.

I think that you know, staff don't realise how much one little tip helps so much. I mean the things like stepping over a line when you freeze is something that I use so much especially when I'm shopping and I suddenly stop and (inaudible) happened before, I was told that tip by a physio, it was really a problem to me, freezing and I was avoiding shopping as much as I could because of the problems it presented. Whereas now I can get going again really quickly so that's very helpful.

I don't consider that I'll deteriorate, I don't think of the negative aspects of it, I just think of today and as I say, so far, so good, nothing's stopped me so far. Just made me do things a bit slower and that's how I think of the future really so I think positively and I'll carry on doing all the things I do; maybe a bit slower in ten years time but that's it.

Thank you very much indeed

That's alright.