# Interview P05\_260721

|  |
| --- |
| * Length of diagnosis – 17 years * X1 medication for PD * DBS stimulation * Made own decisions regarding medications and given autonomy * Poor GP relationship |

**Interviewer:**

**I’d first like to ask you, asking some questions about your Parkinson’s. Um, how long have you been diagnosed with Parkinson’s?**

**Answer:**

17 years

**Interviewer:**

**17 years. Okay. And how was it when you first got diagnosed do you remember?**

**Answer:**

Well I remember I’d had it; I had the symptoms for about 3 years before I was diagnosed. But I didn’t bother to go to the Doctors.

**Interviewer:**

**And why’s that you think?**

**Answer:**

I was just, I just put it at the back of my mind. First symptom for me was I couldn’t click my computer mouse at work and then my handwriting went and after about 3 years it become a bit of a nuisance, so I thought I’d better go and see a Doctor. And she referred me to a Consultant.

**Interviewer:**

**Where was that?**

**Answer:**

In *(city hospital).* And, um, he, he diagnosed Parkinson’s.

**Interviewer:**

**And how old were you when you?**

**Answer:**

Um, that’s 17 years, 53.

**Interviewer:**

**Okay, and so you were still at**

**Answer:**

No, 55.

**Interviewer:**

**55, okay. You were still working at that point?**

**Answer:**

Yeah, yeah.

**Interviewer:**

**And how was that?**

**Answer:**

I noticed I was going off the boil a bit. I’ve got quite a stressful job; I was finding it a bit more difficult.

**Interviewer:**

**Yeah, and um, you know, how long did it take for them to diagnose you with Parkinson’s?**

**Answer:**

Well I went and saw my GP in the summer and by the time, it took a few months, you get the referral through for the Consultant and the diagnosis was straightaway.

**Interviewer:**

**Okay, yeah. and how did you find, you know, getting information about Parkinson’s?**

**Answer:**

Well, Consultant said to me, ‘if you want my advice learn as much as you can about Parkinson’s. Read everything you can; try and find the association and, um, learn everything you can so you can make informed choices about your treatment and medication and things like that’. So, I followed his advice.

**Interviewer:**

**Where did you get information about Parkinson’s?**

**Answer:**

Oh, from Parkinson’s UK; from websites I, I particularly used to use the American Government website, MedlinePlus.

**Interviewer:**

**And how did you find, you know, understanding the information. Was it easy or difficult to understand?**

**Answer:**

Hm, I could understand most of it, but a lot of the medical stuff didn’t know what they were talking about. But the general concept about the side effects of different medication and current thinking on Parkinson’s I could understand.

**Interviewer:**

**And what about the things you didn’t understand, did you ask someone or what did you do about that?**

**Answer:**

I, I was only trying to get a broad of it so I, I didn’t really bother to ask anybody, I just read as much as I could and

**Interviewer:**

**Yeah, and did you find that learning about it, you said, as much as you could – was that helpful or not?**

**Answer:**

I think it’s really helpful because I have had for 17 years and I’m still here.

**Interviewer:**

**Yes. And do you think, over the last 17 years, things have changed, how you get information?**

**Answer:**

No, not really. it just, still the same with my experience.

**Interviewer:**

**So, you still use the websites of Parkinson’s UK and things like that?**

**Answer:**

Yes, yes. I did some research recently into what was causing my eye problem and learnt quite a lot about DBS as a result of that.

**Interviewer:**

**Okay, yeah. So, you talked a little bit about Deep Brain Stimulation, but I suppose before you had Deep Brain Stimulation, when once you were diagnosed what sort of treatments were you given for your Parkinson’s?**

**Answer:**

Nothing .. No, for the first year I didn’t take any medication at all. Um, and then, I took Amantadine for a year, then I went onto Ropinirole. I’m still on Ropinirole.

**Interviewer:**

**And how do you manage your medications with Parkinson’s?**

**Answer:**

Um, this probably sounds a bit daft, but I listen to my brain. And if my brain tells me I don’t like it I don’t take it.

**Interviewer:**

**And do you get, could you try and explain that a little bit more?**

**Answer:**

Well I, I’m very sensitive, I’m very sensitive to medication. I, when they put me on Amantadine, a child’s dose cos I was so, so sensitive to it.

**Interviewer:**

**Was that the side effects or?**

**Answer:**

Yes. I was feeling a bit spaced out of it. And um, I tended to, well I went to a Parkinson’s meeting in (city name) and the chap there who was younger than me, who was, he had mental health problems really badly. And I saw his Carer and she said he was perfectly alright until a few, few months ago. He was given some Parkinson’s medication and it didn’t agree with him but because he was told to take it for 6 months, he took if for 6 months and it did something to his mind. And he never recovered from it.

**Interviewer:**

**Oh dear, yeah. And what about yourself, I suppose seeing?**

**Answer:**

And I thought, I thought if I get the feeling in my brain isn’t happy with it, I won’t take it. And I followed that right the way through. I’m always told I’m under medicated but it’s my choice, you know.

**Interviewer:**

**Absolutely. And you’ve done that over the years with medications?**

**Answer:**

Yes. I tried that with everything.

**Interviewer:**

**And how did you find that, trying the medication and?**

**Answer:**

Well, I’ve started, it’s rather funny because I started off with a good response. And after about 2 weeks it all goes wrong, and my brain would not accept 2 different drugs at the same time.

**Interviewer:**

**And so, what do you do about that?**

**Answer:**

I just stopped taking the one, I stuck to the Ropinirole while I could and I still keep taking that. That seems to work.

**Interviewer:**

**And do you find that you, you know, starting new medications and dealing with the side effects, has that been easy or difficult to manage over the years?**

**Answer:**

It’s been difficult because I was taking some drugs and they completely stopped me from walking. And I just can’t walk at all; I stumble around which I do now anyway cos I’ve had it (Parkinson’s) so long. But this was after I only had it (Parkinson’s) for 5 years.

**Interviewer:**

**Okay, and how does, how has that been over the last 17 years with?**

**Answer:**

I’m now on a lower dose of Ropinirole, as I was on 5 years ago because I found I was getting angry; agitated; anxious. And I, *(PD specialist)* suggested I take a different drug which I took, and I said to her I’m going to reduce my Ropinirole to see if I can accept the new one with a smaller amount of Ropinirole. And I couldn’t, so I stopped taking the new one, but I felt so much better on a lower dose of Requip that I kept on taking it, yeah.

**Interviewer:**

**And those medication changes, has it always based on your Doctors advice or is that something you’ve learned to manage over the years?**

**Answer:**

I tend to make my own mind up

**Interviewer:**

**And do you seek advice from anyone before doing that or?**

**Answer:**

*(PD specialist)* usually.

**Interviewer:**

**Okay, and I suppose, thinking back, you know on all your, the things that you do to help with your Parkinson’s which aspect or thing do you find most challenging to manage?**

**Answer:**

Um, my eyes closing.

**Interviewer:**

**In what way?**

**Answer:**

If I turn my, my deep brain stimulation assimilation up, to control my tremor completely, my eyes will shut every 5 seconds. They won’t open again. If I open them by flicking up my eyelids, they’ll shut again, about every 5 seconds. So, I have it turned right down which I found out it’s the voltage that affects the eyes.

**Interviewer:**

**The voltage affects.**

**Answer:**

Yes. The eyes so, in the brain (interesting) so I turn the voltage down.

**Interviewer:**

**So when, when did you have deep brain stimulation?**

**Answer:**

Um, 7 years ago.

**Interviewer:**

**Tell me about, you know, that process and how you found having that and what happened before and after?**

**Answer:**

Before I had it, I had …24 hours a day, 7 days a week. I couldn’t sleep; I was losing an enormous amount of weight cos I shook all the time. If I sat on the hand, the right hand, the right which was worse, if I sat on it I bounced up and down. It was very bad, and, *(PD specialist)* referred me to *(hospital name)* at *(city),* and they said they’d do it, but I don’t think they were particularly hopefully that they’ll get a good response, a perfect response. But they said they’d do it. And at first it was, I had it turned up quite high, it was quite good, but as the times gone on it’s deteriorated a bit and as I’ve said I’ve turned it right down to try and keep my eyes open.

**Interviewer:**

**So, you had to go to (hospital name) in (city) to have it done?**

**Answer:**

Yeah

**Interviewer:**

**And how was that process?**

**Answer:**

Brilliant. Absolutely brilliant.

**Interviewer:**

**Good. And did you find, you know, how much information did you have about Deep Brain Stimulation before?**

**Answer:**

None. Well I’d, I’d looked it up because it had been mentioned to me before, but I wasn’t on the right drugs to get it. You have to take Levodopa, and I wasn’t. So, I wouldn’t have got it. So, I had to take Levodopa for a short while to get the operation to prove it would control my tremor.

**Interviewer:**

**And you, you said you tried Levodopa you were not on it or?**

**Answer:**

I tried one, I tried Sinemet and that killed me, I came to a grinding halt. I was quite ill on that, so I went to Madopar and that was better. It did control my tremor a little bit, but I got really depressed on it, so I stopped taking that.

**Interviewer:**

**And how did you learn about the Deep Brain Stimulation settings on the Deep Brain Stimulation, how have you found that over the?**

**Answer:**

Gone onto the American Government website; looked up Research Factors. And I got about half a dozen research papers upstairs that I’ve picked around the bits I understand and um, its come up with the sort of things that they found do interfere with stimulation and the things that are beneficial.

**Interviewer:**

**So things that interfere with the stimulations you said?**

**Answer:**

Yes.

**Interviewer:**

**And what sort of things have you found?**

**Answer:**

If you have a high pulse width, it interferes with your speech. And, there is a lot of optimum settings for pulse width and frequency voltage which they start off using and then tweak it from there if it doesn’t work. We’ve been playing around with mine for quite a long time.

**Interviewer:**

**So, you make the adjustments on your own, do you?**

**Answer:**

No, I think I can only adjust the voltage and the groups. I’ve got 3 groups on it, all with different settings (alright) and I can just adjust the voltage up, on the

**Interviewer:**

**So, you’ve 3 groups and you adjust the voltage on it yourself do you?**

**Answer:**

Yes, I can switch from one group to the next, to find out which one’s best. Adjust the voltage and that.

**Interviewer:**

**And how did you kind of learn, learn which is best, you know, for you.**

**Answer:**

Well what we did was that (city hospital) agreed to give me an appointment every 6 weeks. And I produced a chart, of where I want to get to with the settings and each time I went u they’d adjust one of the channels. I start off with both channels, A and C Channels the same, and then they adjusted one of them. And I tried that for 6 weeks to see if it was better than the previous one. And then we changed the other one; we sort of leap-frogged each channel. Kept one the same and changed the other one.

**Interviewer:**

**Yeah. so, you had regular appointments (yes) trying to determine the right settings for you?**

**Answer:**

Yes. When we first started I couldn’t talk, it interfered with my brain so much I couldn’t talk. But now I can at least talk.

**Interviewer:**

**So, you monitored your response really, you were saying**

**Answer:**

Yes, yes.

**Interviewer:**

**What sort of things did you write, you said you wrote a chart to see what you wanted to get to? What sort of things were you looking at?**

**Answer:**

Well, I wanted to be able to talk. I wanted to try and reduce my eye closure; and I wanted to be able to control the tremor at the same time. And I had a target to get to for the pulse width and a target to get to the frequency, a range of voltages that I wanted to try and get to, see if I could get to it. But once I got my speech back, I was a lot happier.

**Interviewer:**

**And do you still go a lot of appointments or, appointments with**

**Answer:**

Well it all stopped due to Covid. (alright, okay) and I haven’t heard from them for about a year. I don’t know what’s happening. I will have to e-mail them.

**Interviewer:**

**Did you used to have to regular appointments with them?**

**Answer:**

Not at first. Only annual appointments for the first, for the, after we got over the initial stages of setting it up. I went to annual appointments for about 3 or 4 years.

**Interviewer:**

**And how long did the initial stages last?**

**Answer:**

What the initial setting up? Well, when they first set it up it lasted for about a day. And then it all went haywire, and we slowly got it a bit more stable. Once it was stable, it took about a year.

**Interviewer:**

**It took about a year for it to get stable.**

**Answer:**

Yes (wow). to find the settings that would. My right hand tremor was so bad…

**Interviewer:**

**And did you go to (hospital name) every time for your appointment?**

**Answer:**

Yes, yes.

**Interviewer:**

**And how was getting to the appointments, how did you find that?**

**Answer:**

Well we ended up staying in a Hotel because it, it, it’s not a very nice drive. And (wife) was having to drive. And so, we decided it was too much to try and get there for 9 o’clock in the morning and, even 10 o’clock. It was too big a risk that we’d get stuck in traffic; miss the appointment. So, we decided to stay in a Hotel every time.

**Interviewer:**

**How many appointments do you think you had over?**

**Answer:**

Oh, crikey. Over the course of 7 years, about 20 appointments.

**Interviewer:**

**And, I suppose thinking about, you know, any other things, you know, you talk about some of the medications you take, how many medications do you take for your Parkinson’s?**

**Answer:**

Well, all I take is 12mg of Requip XL.

**Interviewer:**

**Okay. Do you take any other medications?**

**Answer:**

I take a laxative. They’re the only two I take, a laxative and Requip.

**Interviewer:**

**And how do you manage your medications and prescriptions?**

**Answer:**

I do my repeat prescriptions online and, take my medication every morning.

**Interviewer:**

**And do you find that easy or difficult?**

**Answer:**

Easy. But I’ve had. The things that have troubled me are mainly revolve around my GP.

**Interviewer:**

**Tell me about that. Tell me about what you’ve experienced?**

**Answer:**

Well it’s very hard for (wife) with me like this. She has to do everything that I used to do as well around the house. So, she, I try and protect her as much as I can, but the GP, they’ve got no empathy at all. They do things that upset me and then she has to sort them out.

**Interviewer:**

**Just tell me your experiences and what you’ve experienced that have been difficult**

**Answer:**

Well, well when I’d had Parkinson’s for about 6 years I was put on the generic replacement for Ropinorole cos it was cheaper. And it didn’t agree with me. My Parkinson’s became very unstable and a lot of side effects. And I, I argued with my GP, it’s the generic Ropinorole that’s doing it and they said it’s the same. So, in the end I did some research and found it wasn’t the same.

**Interviewer:**

**So, you researched things yourself**

**Answer:**

Yeah, and found it wasn’t the same. And, the American Government didn’t recommend using generics. I know you’ve got to look at the commercial side of that and the drug companies in America but. And finally, I got so cross with them that I phoned up the Parkinson’s Nurse, (*name).* And I’d been on it for about 18 months, I’d been quite bad, and I said to her ‘I’m sure this generic medication isn’t doing me any good; it isn’t working; its not doing any good’. And she said I think you’re probably right, and she immediately phoned my Doctor up and told him to change it. And they did.

**Interviewer:**

**But you were on the generic for 18 months**

**Answer:**

Yeah. But I, I got quite, quite unpleasant side-effects. I had to wash myself about three or four times a day cos I sweat, and I smelt awful. As soon as I started taking the Requip again, it all cleared up, apart from my swollen legs.

**Interviewer:**

**And what do you think was the most difficult thing about that interaction with your GP. What was frustrating about that?**

**Answer:**

They seemed convinced that it was the same. And it happened again, last year. I had the flu and they changed my drug to a generic one.

**Interviewer:**

**So, it happened again last year?**

**Answer:**

Yeah. they didn’t consult me; they didn’t tell me. I went online to do a repeat prescription and they changed it.

**Interviewer:**

**And how did you go about talking to them again?**

**Answer:**

(wife) phoned them up and lost her temper with them because they tried to tell her I’d been on them for a year. And they changed my record, to try and show I’d been on it for a year. And when the GP realised, they had had some sort of audit for it from NHS England and they’d changed all the prescriptions to the cheapest drug.

**Interviewer:**

**So, they, the GP said they had an audit from NHS England**

**Answer:**

Yes, and they changed all the prescriptions to the cheapest generic one without looking at medical record or anything. And err, it’s now written on my repeat that I must only take Requip.

**Interviewer:**

**So, they’ve now put it on, put it on your repeat prescriptions specifically**

**Answer:**

Yeah, but I was so cross with them. (absolutely) I thought to do that, without even telling me or looking at my records, and to change a year’s history. Because the GP said to (wife), well you’re already on it for over a year. And she said, ‘no he hasn’t’. and, err, that was it.

**Interviewer:**

**And do you see your GP for, for anything?**

**Answer:**

No. haven’t seen him. Wouldn’t even know if I passed him in the street. I have never seen my new GP (really). Yeah.

**Interviewer:**

**So, do you, I suppose most of your appointments are with the Parkinson’s Team?**

**Answer:**

Yeah

**Interviewer:**

**And how have you found, you know, your appointments with the Parkinson’s Team?**

**Answer:**

Well I think they’re the only thing that’s kept us sane I think.

**Interviewer:**

**Kept you sane**

**Answer:**

Yes.

**Interviewer:**

**What do you think, you know, what do they help you with?**

**Answer:**

They’re great at suggesting things. But they also leave the decisions to you whether you do it or not, which I think is great.

**Interviewer:**

**And who do you see. So, you know, what’s**

**Answer:**

The Parkinson’s Nurse (name). And I saw (PD specialist).

**Interviewer:**

**And do you also see, you know, other members of the Healthcare Professions such as Physiotherapists, Occupational Therapists?**

**Answer:**

I’ve seen a physio in the past. And I’ve been to Speech therapy.

**Interviewer:**

**How have you found those appointments?**

**Answer:**

They’re, they’re good, but there’s the … you only get a short number of seconds. Sorry, my tremor is going to go mad now Um, but, I go to the gym once a week and see a Personal Trainer and that helps a lot.

**Interviewer:**

**Is that something you thought to do on your own?**

**Answer:**

Yeah. I used to play golf. But now I can’t play golf I needed something to keep fit. So, I joined the gym. And that’s helped a lot.

**Interviewer:**

**In what way?**

**Answer:**

Kept me muscles, muscle strength up and kept me mobile. But I can’t walk now, not very far anyway. I’ve got no sense of balance.

**Interviewer:**

**So, going to the gym has been helpful with that?**

**Answer:**

Yes, very helpful.

**Interviewer:**

**And how have you found, um, you know, if you ever needed access to help or healthcare, um, out-of-hours or at the weekends. Have you had any problems with that? Or needed to.**

**Answer:**

Well yes. Last year we had a fright in the middle of the night. (wife) woke up with a pain in her chest and we thought she was having a Heart Attack. And we called an ambulance and they, they were absolutely brilliant.

**Interviewer:**

**And have you had any problems with your Parkinson’s’ that you needed help?**

**Answer:**

I had an intense pain in my side once, we had to call them out for, that’s all.

**Interviewer:**

**And how was that experience, what did you do?**

**Answer:**

That was good. They sent an ambulance out and explained the pain would begin to subside and they stayed until it had gone.

**Interviewer:**

**Oh well, that’s good.**

**Answer:**

But when they came to help (wife), they realised I was disabled and called my daughter to come and ask her if she’d come across.

**Interviewer:**

**And who, obviously (wife) helps you with your Parkinson’s. do you have any other help, from family or?**

**Answer:**

We have a Nurse that comes privately once a week, well 6 times a week once a day.

**Interviewer:**

**Is that a private, you pay for that privately?**

**Answer:**

Yeah, yes.

**Interviewer:**

**And how did you find, you know, getting information about where to get help**

**Answer:**

Well funnily enough it’s a daughter of a friend. And she’s always said that if we got to the point where we thought we wanted help; she would fit us in. she’s a free, Freelance Carer.

**Interviewer:**

**So, she comes in once a day.**

**Answer:**

Yes, to help get me washed and dressed and fed in the morning. It gives (wife), it means (wife) hasn’t got; she can go and do something that she wants to do while the Nurse is here.

**Interviewer:**

**That’s very helpful. And, what do you do if you have a, a concern or question about your Parkinson’s?**

**Answer:**

I usually save them up for when I see (*PD nurse specialist*) or the Consultant, whoever that will be.

**Interviewer:**

**You save it up do you?**

**Answer:**

Or I look it up myself. See if there’s any research on it.

**Interviewer:**

**And, tell me about your experiences of getting hold, if you ever needed to get hold of the, *(PD specialist)* or *(PD nurse specialist)* before your appointments?**

**Answer:**

*(PD nurse specialist)* is the only one I’ve had to get hold of in-between appointments. And she, I didn’t used to see her very much and we left it that if I ever needed her I’d phone. And she responds very quickly.

**Interviewer:**

**So, you phone her do you?**

**Answer:**

Yes, I do.

**Interviewer:**

**Is that quite easy or difficult to get hold of her?**

**Answer:**

She’s quite easy.

**Interviewer:**

**And how has it been getting to your appointments. How do you find that, is it easy or difficult?**

**Answer:**

It’s easy as (wife) still driving

**Interviewer:**

**So (wife) drives?**

**Answer:**

Yes I sit and relax back. I thought with my eyes closing it’s not one of the best things to happen when you’re driving

**Interviewer:**

**And um, I suppose, how long does it take you to get there?**

**Answer:**

It’s just down the road. It’s about 10 minutes. Parking’s a bit of a problem sometimes. I’ve got a Blue Badge and everything.

**Interviewer:**

**You’ve got a Blue Badge to help with that**

**Answer:**

Yeah.

**Interviewer:**

**And how often are your appointments.**

**Answer:**

I do every 6 months with (PD nurse specialist). Every 6 months with the Consultant but, each one’s 3 months after the other. So, it’s, the Parkinson’s nurse, then the Consultant then Parkinson’s nurse

**Interviewer:**

**And how do you find the appointment itself?**

**Answer:**

Its good. I don’t like telephone appointments

**Interviewer:**

**So, you don’t like telephone appointments?**

**Answer:**

Because of my speech. Then I start to shake like mad. Every time I have to challenge my brain, I shake.

**Interviewer:**

**And um, do you think there’s been any changes because of Covid that you’ve found with your appointments?**

**Answer:**

Well they’ve been mainly telephone appointments due to Covid. The main implication with Covid is my mobility’s taken a big hit. I’m just not as good on my feet as I was before.

**Interviewer:**

**So, your appointments have been telephone for one, you’ve not been going out as much.**

**Answer:**

No.

**Interviewer:**

**And obviously you said telephone appointments you don’t like them?**

**Answer:**

No. Because I can’t speak loudly enough for the phone to pick it up.

**Interviewer:**

**And that’s been quite challenging then?**

**Answer:**

Yes, yes.

**Interviewer:**

**I suppose, how do you think your care has been co-ordinated, you know, between *(PD nurse specialist)* or the Consultant or your GP and all that communication between the services. How do you think that has been?**

**Answer:**

*(PD nurse specialist)* and *(PD specialist)* is good. Anything they send to my GP they seem to ignore. I don’t think they even read the letters. I get no reaction from GP at all.

**Interviewer:**

**So how do you manage that?**

**Answer:**

*(PD specialist)* writes out what, if she has to change my medication, she writes it on a document for us and we drop it in, and they do it. But they don’t enquire how (wife) is as my Carer or anything.

**Interviewer:**

**So, you get very little contact with your GP by the sounds of it**

**Answer:**

I try to avoid them now.

**Interviewer:**

**Do you think, you avoid them because of the experiences you’ve had with your medication, or was it?**

**Answer:**

Yes, and the last appointment I had with a GP, he said to me ‘you’ve had 10 minutes now; you’ve had your time, time for you to go’. I thought, ‘oh fine’.

**Interviewer:**

**I suppose that’s, that’s clearly why you said you try and avoid them now cos they’ve clearly had an impact**

**Answer:**

Yes. I used to have a really good GP, but she retired.

**Interviewer:**

**And thinking about those, are there any other things that you do to help your Parkinson’s. You’ve talked about, you know, some of the medications you take; managing your Deep Brain Stimulation; you know, going to the gym to help with the exercise. Is there any other things that you, you also do to help your Parkinson’s that perhaps we haven’t covered?**

**Answer:**

Um, I try and be careful what I’m eating. Certain things I try and avoid it if I’m doing anything that requires going out.

**Interviewer:**

**Okay, why’s that?**

**Answer:**

Cos it interferes with the, with the absorption of Requip.

**Interviewer:**

**So, you find that certain foods interferes with the medication absorption. So how did you find out, or what were your experiences with it?**

**Answer:**

Reading articles in the Parkinson’s Magazine. Like cheese, I love cheese, but it blocks the Ropinirole. So that’s out now.

**Interviewer:**

**So, you said that you try and, you have to plan it if you’re going out with your medications?**

**Answer:**

I just avoid certain things. If I know I’m going to be active. Up until recently I, I still walk quite a lot with a walker. But if we’re going out anywhere, and I know I’m going to have to walk then I try and avoid rich foods and cheese; coffee, it makes me shake.

**Interviewer:**

**And, Ropinirole you take once a day?**

**Answer:**

Yes.

**Interviewer:**

**And the laxatives you said you take?**

**Answer:**

One, once a day, every night.

**Interviewer:**

**Every night. You take your Ropinirole in the morning and the laxative at night.**

**Answer:**

Yeah.

**Interviewer:**

**Um, and, anything else that you can think of?**

**Answer:**

I think I’m lucky that I’ve got (wife). Really, really lucky. She does so much for me. And, she’s had to take on a lot of things that I used to do. Daft things like checking the tyre pressure on the car and doing the oil and the windscreen washer bottle, doing the garden; DIY work, she can use a power drill now, and things like that. We tend to get along quite well. She loses her temper with me sometimes, but I accept it must be very difficult for someone to have to put up with someone like me.

**Interviewer:**

**And, I suppose thinking about the impact of, you know, I suppose the impact of Parkinson’s in your life and social networks. What do you think that has been?**

**Answer:**

It’s stopped us doing what we thought we were going to do when I, we retired. We used to do a hell of a lot of walking; we’d go out and walk all day. Take out lunch and plan a walk and walk for about 10 hours. And we can’t do that. And we used to see groups, rock music mainly and all things like that. Our friends have been really good; we still go out as a group of eight for a meal. They accept me as I am now.

**Interviewer:**

**And does, you know the things that you have to do for your Parkinson’s, such as managing medications or Deep Brain Stimulation or your diet, does that impact on your life or social networks at all?**

**Answer:**

I’ve come to accept it.

**Interviewer:**

**You’ve come to accept it. And do you think, you know, managing your Parkinson’s while you were working when you were first diagnosed. Do you think there was any impact off that or?**

**Answer:**

No, cos I didn’t know that I had anything that serious wrong with me. I thought it was something wrong in my arm cos I didn’t have a tremor then. And um, I just thought I had something my arm cos my writing faded. I couldn’t write more than a page; me arm would just stick out and I thought it was something wrong with my arm, my arm.

**Interviewer:**

**And how long after being diagnosed with Parkinson’s did you retire?**

**Answer:**

Um, 2 years, but I’d had it for 5.

**Interviewer:**

**And you hadn’t started medication, you didn’t start medication until a few years after being diagnosed you said?**

**Answer:**

No. I, I, had 3 years before it was diagnosed; then I had it for a year after diagnosis without medication. The year I started medication that had been for a year when I retired.

**Interviewer:**

**And you’ve been on that ever since**

**Answer:**

But (wife) and I sort of agreed that she’d rather have me as I am, but mentally alert, than being able to walk and not being mentally aware of what’s going on. So, we tended to do things to keep me mentally strong, but we’ve had to accept that the physical implications of doing that.

**Interviewer:**

**So, you, you agreed that, so that’s a discussion you’ve had – to be mentally alert and not being drowsy as you said before was more important than walking.**

**Answer:**

Yes, because she can leave me on my own and go out with her friends. Whereas if I was mentally not with it so much, she wouldn’t be able to.

**Interviewer:**

**And do you, do you um, do you feel overstretched with what you do for your Parkinson’s?**

**Answer:**

No. I’ve, we’ve been together so long. I still, people who haven’t got Parkinson’s I think find it difficult to understand what’s happened to people who have got it.

**Interviewer:**

**So, you think that unless you’ve had it yourself**

**Answer:**

Yeah, you don’t understand what. You sort of tell them about the message isn’t getting through from my brain to my leg and they can’t understand that. And the fact that I have to think; move foot; freeze; swallow; keep eyes open; and if someone speaks to you, it all goes haywire. I say to people, your messages go through your brain into your foot by e-mail, mine go by second class post. And sometimes, they don’t get there.

**Interviewer:**

**So, a very interesting comparison there. Very true. It’s a one, good way of describing it.**

**Answer:**

And if my brain can’t work out which foot to move, it moves them both or neither of them.

**Interviewer:**

**I suppose, how, a question if you can think how the Healthcare System can be changed to help you manage your health with Parkinson’s. what do you think could be improved or could be better from your experiences?**

**Answer:**

I think my dissatisfaction with the Healthcare System is my GP Surgery. But then, I don’t want them interfering. I’m caught. In some respects, I’m quite happy really with how they are, and not interfering. I like to be able to have a say in my own treatment. I’ve always found that possible with the Hospital.

**Interviewer:**

**So, with the Parkinson’s Team you feel you can make your own decisions and your own say (yes).**

**Answer:**

Yes. You come back to what the first Consultant said to me about learning as much as you can and then so you can make informed judgement about what is being suggested to you.

**Interviewer:**

**That’s very interesting. Is there anything, you know, that’s important to help manage your Parkinson’s that we haven’t discussed or talked about?**

**Answer:**

No, I think a lot. I think a lot it you’ve got to help yourself. I’ve been lucky that I’ve got a good pension so I can afford to have the Personal Trainer once a week, for an hour. But I accept that a lot of people, if you’ve only got your State Pension you wouldn’t be able to afford it. So, I think I’ve fairly privileged.

**Interviewer:**

**Have there been any financial expenses related to your Parkinson’s over the years?**

**Answer:**

Yeah. I’ve bought a walker to help me walk. (wife) and I decided we are going to get a wheelchair this summer, so we’re waiting for a wheelchair at the moment, because if we go out for a day I’m getting really slow on my walker and get really tired. Having to sit down a lot and I’m bent over. So, I can’t talk to anybody ,even if I meet someone I know, I can’t talk to them. And I’m always frightened of falling over with my eyes shut. So, we decided, that it was time for me to have a wheelchair just to use if we go out for a day and go to the Gardens. I can go out to the Gardens in the wheelchair, and it’ll be more relaxing. So that’s the state we’re in at the moment, we’ve got to the point where I, I’m finally accepted I’ve got to have a wheelchair, which was a difficult decision to make. (absolutely) I can’t remember what the question was now.

**Interviewer:**

**Any, just, you know, we talked any financial expenses and you talked about**

**Answer:**

Oh yeah I bought a wheelchair.

**Interviewer:**

**Walker and a wheelchair, yeah**

**Answer:**

Which is quite expensive. I can’t have an electric I can control myself due to the tremor, it might be a bit rough on the throttle. Might find I end up in the pond.

**Interviewer:**

**Any other financial expense that you, the nurse, the private nurse**

**Answer:**

The Nurse

**Interviewer:**

**the nurse, the private nurse**

**Answer:**

Yes,

**Interviewer:**

**Have you looked into, I suppose, organising care through the Council or Social Care?**

**Answer:**

Well, yes in a way. (wife’s) mother had care before she died. And going on the financial assessments needed for her, I wouldn’t get, wouldn’t have a chance of getting anything. I get Attendance Allowance, so that pays towards it. But I get a good pension so I can afford to have a private Nurse.

**Interviewer:**

**I suppose, you were talking, you talked about somethings that helped out, have been your pension, (wife) and, you know, computers and looking up the internet about things you need to know about. Is there anything else you think you have that helps you manage your Parkinson’s and all the things to do for it?**

**Answer:**

A sense of humour, you’ve got to have a sense of humour.

**Interviewer:**

**Yeah, yeah it’s important.**

**Answer:**

I, I think it is. You’ve got to laugh at yourself and accept people laughing at you. We used to have a Branch of Parkinson’s UK in (town name); well I was involved in that. Some people did a collection outside Tesco’s, a street collection with tins. And they were told by Tesco’s that they couldn’t shake the tins. It’s a bit difficult with Parkinson’s. We had a bit of a laugh about that.

**Interviewer:**

**And did you find Parkinson’s UK helpful throughout the years or not so helpful**

**Answer:**

They are helpful but I think sometimes they’re very close to NHS England. A bit too close. They don’t want to rock the boat. When I raised questions, about generic medications and that not much work has been done on it. And they tried to tell me it was all in my mind. And I found that very difficult to accept. It rather coloured my judgement of Parkinson’s UK.

**Interviewer:**

**So, you spoke to them about your issues with your medications, did you?**

**Answer:**

Yes. I raised it at a meeting when there were actual researchers down, one of our Branch meetings. And I raised it as a question at the meeting, and got told it was all in my mind. (wife) found out afterwards that she, she heard, and she was taken off, I think. I found that a bit, not what I expected.

**Interviewer:**

**Anything else we haven’t covered that you can think of before we finish?**

**Answer:**

A lot of responsibility falls on the shoulders of your partner when you have Parkinson’s. I don’t think that’s recognised enough.

**Interviewer:**

**Yeah, absolutely. Something, very important to recognise that.**

**Answer:**

Yeah. when, if anything makes it harder, anything that makes it harder for the partner to look after the person with Parkinson’s should be avoided, like the GPs Surgeries. They should make life easier for you not harder.

**Interviewer:**

**That’s important absolutely.**

**Answer:**

Yeah, cos they’ve got enough to do as it is. You do rely on your partner a lot. We have a laugh.

**Interviewer:**

**Good. Thank you very much**

**Answer:**

I don’t know if that fits with what other people have said.

**Interviewer:**

**Well every experience is different so it’s really interesting, you know, hearing your experiences.**