# Interview PO3\_290621

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| * Length of diagnosis – less than 1 year * Had a folder for all health letters and information * 4 different medications, 1 for PD * Lives with wife (carer) * No POC |

**Interviewer:**

***I’d just like to start by asking you few questions about your Parkinson’s. when were you diagnosed with Parkinson’s?***

**Answer:**

Well it would have been, um, at the end of 2021,

**Interviewer:**

***2020 or before that?***

**Answer:**

No, can’t, just trying to, just looking at my. Sorry about this. I’ve got all, everything documented. Um, I do apologise.

**Interviewer:**

***No, no there’s no rush.***

**Answer:**

We have now confirmed your diagnosis of Parkinson’s and so I will ask *(PD nurse)*, Parkinson’s Nurse Specialist, and that was dated the 21st of October 2020.

**Interviewer:**

***Okay. And, um, how long was it till you got diagnosed, and what happened before that?***

**Answer:**

Um, well I went to see my GP, *(GP name)* um, and, because I’d had a couple of falls in the garden. Um, and well, ripped, things and, you know, and made a bit of a mess of myself (*oh dear).* I went into *(city name)* to the *(local hospital 1*), to the,

**Interviewer:**

***To the Walk In Centre?***

**Answer:**

The Walk In Centre, that’s right and they dressed me and what not. Um, um, but I was actually up ladders doing, well you can we we’ve got lots of hedges and things and so I have to do. Over the years I have always maintained the hedges and the cutting, and I had a couple of falls. Um, oh, and I had a fall in next door, in the snug, our room next door. Um, that was just clumsy; I tripped on something. Um, so I went along to see *(GP name)*, and he said, I mean he has been so good with me over the years. I mean I’ve known him since he joined the Surgery, um, and became a partner. And, um, I mentioned what had happened and he said to me ‘it sounds as though it could be Early Onset Parkinson’s’. And he asked me a strange question, he asked me whether I drooled, and I said ‘no’. And then I realised actually I do drool every time I eat, even if it’s just a sandwich I do dribble and I hate that.

**Interviewer:**

***And how long did it take, you know, from when you saw (GP name) for, to when you were diagnosed?***

**Answer:**

Well, if I, the diagnosis was on, in October 2020 so it would have, I would have seen *(PD specialist)*, um, once before then. Um, with *(PD specialist)*. That, so that was September 2020 that I had a consultation with her, so it was quite, it was quite quickly although she didn’t seem terribly concerned. And I’m sorry but I don’t really understand Parkinson’s, um, and what the prognosis could be, or is. Um, but, I’m waffling.

**Interviewer:**

***So, I suppose part of that, did you get any information about Parkinson’s that you remember?***

**Answer:**

No. No, not until I saw *(PD specialist)*, um, and, well we talked about driving; insurance and I subsequently wrote to, when I had the diagnosis, I wrote to our insurers, um, and they seemed quite happy that I could, that I was covered provided um, provided the DVLA were satisfied. And it must have been round about then that it, I mean this is going back to October, November 2020 that *(PD specialist)* actually wrote, or was in contact with the DVLA and they sent me a great long questionnaire to fill in, and I subsequently, I mean it’s taken ages, but they have um, this is dated the 3rd of December. Um, ‘I’m writing to keep you updated on the progress of our enquiries. We have written to *(PD specialist)*, err, um, ‘as soon as we have received the information we will write to you to let you know further progress. You’ll need to contact us if you have any new information’. And this, that, so that was the 3rd of December 2020, and I eventually got a letter from them, um, to be honest it’s dragged on.

**Interviewer:**

***Is that just the DVLA and the driving?***

**Answer:**

Yeah.

**Interviewer:**

***And what about other information about Parkinson’s’?***

**Answer:**

Well,

**Interviewer;**

***I suppose it’s whether you***

**Answer:**

Not, not, I mean. What I know about the aetiology of Parkinson’s? Is there any sensible information which says it is caused by, it could be as a result of? I mean *(PD specialist)* actually sent me down to *(local hospital 2)* for a scan, and that came back clear. But there’s all this talk that Dopamine all the time, and I don’t really underst, don’t really understand it.

**Interviewer:**

***And I suppose what do you do if you, if you wanted to know more information or was that quite easily, or difficult to understand things about Parkinson’s?***

**Answer:**

Well the thing is, I’m not a great one for dwelling on things, going into, you know, Googling things and what now. Um, but I did, had a letter back from the DVLA on the 13th of April 2021. It says ‘from information we’ve received you satisfy the medical standards for safe driving. I am pleased to tell you that you may keep your Group 1 Driving Licence. If you wish to discuss the matter with your GP you will have to take this letter to show them. If your condition gets worse, or your Dr tells you not to drive please let us know’, so that was quite reassuring that they eventually, after what, what was nearly 2 years came back and said I can keep my Licence. Um, but they also sent me a lot of information on this.

**Interviewer:**

***Okay, so that’s Selegiline.***

**Answer:**

Yes. What is Selegiline?

**Interviewer:**

I’m not sure. Is that a medication that you take, or was that sent to you by the DVLA?

**Answer:**

No, they sent to me

**Interviewer:**

***Was that the DVLA that sent it?***

**Answer:**

The DVLA sent to me. They said ‘if you are currently being treated with, or start being treated with Selegiline please be aware that if you are tested by Police for drugs or accused of Drunk Driving and are asked by the Police if you are taking any medication you should declare you’re use of prescribed Selegiline’.

**Interviewer:**

***But you don’t use that?***

**Answer:**

I don’t use that, no.

**Interviewer:**

***That’s right, okay (no, so it) I suppose then if you wanted to know more about Parkinson’s itself, um, you know, where would you look for information, or who would you contact?***

**Answer:**

The thing is that *(PD nurse)* was very helpful in sending me information on Groups, local Groups that are, but I’ve resisted the temptation to get in touch with the Groups. The reason being, that, you know, it couldn’t have come at a worse time with, um, I don’t know if I’m making any sense.

**Interviewer:**

***Is that the local Support Groups that (PD nurse) has, has directed you towards?***

**Answer:**

Yeah, but I’m just trying to find it, I’m sorry, I’m, I’m, for some reason or another I thought you’d probably have copies of this, um, information.

**Interviewer:**

***I wouldn’t worry too much about what’s in there. It’s mainly just to understand your experiences, so, um, what you thought about having Parkinson’s so far so I wouldn’t worry too much about what’s in the folder, we’re not particular about any precise dates or anything like that. Um, and, do you have any other medical conditions other than Parkinson’s?***

**Answer:**

No, I don’t. (*okay)* No, this is the annoying thing because as you see we’ve got a big garden; it needs a lot of attention; work and it’s physical and it’s quite difficult to maintain. And I’m, I’m just, I’ve got to the point, no I’ve long since got to the point where I feel absolutely exhausted. Not just tired, but exhausted, um, and that, not, I can’t get motivated to do things. I mean the thing is, I don’t sleep anyway, I mean that’s’ that’s historical, but, I find now that I could easily go to bed this afternoon and I’d go out like a light.

But when I go to bed at night, I takes me ages, my mind seems to whirr, nothing in particular and (wife) is so strong and so positive and so supportive. I mean we’re both, our late 70s, approaching 80. We celebrated our 55th wedding anniversary a couple of weeks ago (*Congratulations*), so, you know we know one another pretty well and can be fairly honest with, we can be very upfront with one another. Err, it’s getting to the point now where (wife) is annoying me because she’s, she, she wants reasons as to why I’m feeling like I am and I can’t give those, I don’t understand why. I mean I’m on a whole raft of drugs, Co-careldopa.

**Interviewer:**

***What medications do you take?***

**Answer:**

I’m just going. I take Co-careldopa 3 times a day and then a modified release version at night. Um, and I also take Omeprazole, now the reason for that is because some years ago I had a bout of difficulty swallowing and I was referred to ENT people and in the end they decided it was Reflux. And, and I take Omeprazole, 20 milligrams at night, morning, and night, twice a day. And then, um, I take, I self-medicate on Ibuprofen purely because I find that I wake in the morning I’m very uncomfortable; low back pain; stiff shoulder; my left shoulder particularly. Um, trying to find. I also take err, a drug Lorazepam which you probably won’t be familiar with but it’s a Benzodiazepine that I use, um, for, as a half to one tablet a day for helping me to sleep.

**Interviewer:**

***So how many different times of the day are you taking medications?***

**Answer:**

I take, let me give you chapter and verse. Ah, right, Co-careldopa 25/100 once at night, that’s modified release, once at night. And then I take Co-careldopa 25/100 at 7 o’clock when I get up in the morning; at midday 13.00 hours and in the evening, so 3 times a day. That’s first thing in the morning when I get up; round about lunchtime, I don’t know how important is it to be precise on the timings?

**Interviewer:**

***Well I suppose it what, how you’ve experienced it if you’ve either been delayed or taken in advance, have you noticed any difference? (no) No, oaky.***

**Answer:**

And I mean, over, over time I’ve noticed um, that I’ve not always taken it according to the appointed hour, um, but I haven’t noticed that’s made any difference. Does that make sense?

**Interviewer:**

***Yeah, of course. And how have you found managing all your medications that you take?***

**Answer:**

Well, okay cos (wife)who as I say is very strong and very focussed, she always carries Co-careldopa the 25/100 standard dose, she always carries a couple with her just in case we happen to be away at the time when she thinks I should be taking it.

**Interviewer:**

***And I suppose she thinks you should be taking it; do you feel that you need to take the medications as well?***

**Answer:**

Well I’ m not sure it’s doing anything. Um, I mean I’m not sure what it was supposed to do? What was it supposed to do?

**Interviewer:**

***Well, I think it’s meant to help with your symptoms and your movement and how stiff you are usually. And some, different people experience it differently, and you’ve obviously don’t think you’ve noticed much difference when you take them***

**Answer:**

No, I mean, I, I continue to be clumsy, sadly. Um, I mean I’m very familiar with this room, but I will still bump into things if I’m walking through the room. And in the mornings I always take (wife) a mug of tea in bed, and she has a cup of tea in bed, and I have great difficulty, you notice our stairs are very steep anyway, and I’m very unsteady. Um

**Interviewer:**

***And that’s in spite of taking your medications?***

**Answer:**

Yeah. Cos, I mean when you come to talk to (wife) I think she will say ‘can we do anything to change the medication?’ One of the things that *(PD nurse)* suggested was that I take um, Mirtazapine, yeah Mirtazapine. Um, and I’ve not taken up her advice to contact um, the various Groups because I’ve been very concerned about myself about Covid, and I’ve not wanted to be with people *(of course)* who possibly can put me at risk and therefore the family at risk *(yeah, absolutely*). Err, so, I’m waiting to see, for things to improve. Um, I’ll then take *(PD nurse)*’s advice; she’s, I mean she’s given me um, she’s given me some e-mail *(contacts)*, yes e-mail contacts.

**Interviewer:**

***I suppose in terms of what you’ve been given, you’ve clearly got a folder there that looks after all your medical information and on health, is that right?***

**Answer:**

Yeah this is simply for, this is simply um, for the Parkinson’s. This is my Parkinson’s file.

**Interviewer:**

***When did you start that?***

**Answer:**

From, from, right from the beginning. Um,

**Interviewer:**

***And why, why was that, why did you think, why did you start it?***

**Answer:**

Cos I said to .. well I tend to be like you know, (*yes*) I tend to be horribly organised, with some things. Um, I, yeah, I’ve got the notes here, that, from my first consultation with *(GP name)* where I said ‘things over several months I’ve become unstable; unsteady; clumsy and poor balance. Over the same period, I’ve become more forgetful and confused; had a fall a month or so ago. Initially had back, had back pain’, um

**Interviewer:**

***So, you write down notes and, and you monitor your symptoms and health I suppose.***

**Answer:**

I do. But the thing is. What’s the worst that can happen to me? Having got this condition. Let’s say I have got Parkinson’s; let’s say the diagnosis was correct, what’s the worst thing that can happen.

**Interviewer:**

***I mean, probably we can address that later after the interview. Um, and obviously that’s something you can talk to (PD nurse) and (PD specialist) about and we can try and talk. Now I’m just focussing on the questions that I have to ask, and we can address that after the interview if that’s okay.***

**Answer:**

Yeah, and I’m not sure I’m making much sense to you.

**Interviewer:**

***No, no you’re doing fine. Um, I suppose in, other than your medications, um, how do you find the appointments that you’ve had with your Parkinson’s so far. So, all the appointments, you know, you’ve already talked about seeing (PD nurse) and (PD specialist) and other, are there any other Professionals that you’ve seen?***

**Answer:**

No, no other Professionals. I’ve just seen *(PD nurse)* and *(PD specialist)* and I’ve found those consultations, face-to-face consultations helpful.

**Interviewer:**

***And you’ve had some telephone ones you said?***

**Answer:**

Yeah, I had one telephone one with *(PD specialist)*, because there was a leak at *(local hospital 3)* and she had to change everything, so we did it over the phone. But I think we more or less agreed that it wasn’t the ideal way of doing it and she did write to me, subsequently, and apologised for the fact she’d had to change.

**Interviewer:**

***Yeah, yeah. And you were telling me that you’re not, you weren’t too keen on a telephone appointment coming up.***

**Answer:**

No, very much. No, I, I, people need to see me, do you know what I mean? I, I feel people need to see me.

**Interviewer:**

***And what is helpful, what do you find helpful about the appointments?***

**Answer:**

The fact that people can be reassuring

**Interviewer:**

***Yes, of course. And are there things that are perhaps more challenging or difficult?***

**Answer:**

Well, I’m, I’m definitely not improving. I feel that I’ve regressed, and I’m not moving forward. And the fact that I can’t talk to (wife) and explain, I can’t get her to understand, you know, when she says, ‘what’s worrying you?’, I can’t explain to her what’s worrying me. Um, you know, it’s difficult because I, I’ve got young grandchildren um, who I adore and I’m not sure I can give enough to them.

**Interviewer:**

***Of course, yes. It sounds as if it’s been quite difficult, um, since being diagnosed with Parkinson’s.***

**Answer:**

Oh, it is. Its, its miserable. Its miserable because I am, I’m not feeling so, at the moment but I’m so active. (wife) has a business, which I help her with, and it’s to do with Interior Design, and furnishings and what not. And so, I do a lot of the, um, restoration work but the thing is, I’m, I’m beginning to notice that my hand/eye co-ordination is not, is not as it was, you know. I can’t use, I can’t do fine things.

**Interviewer:**

***And I suppose, thinking about all you do to look after your health, and we’ve talked about some of the things like the medication; and going to appointments. Are there anything else that you do to try and look after yourself with Parkinson’s.***

**Answer:**

Yeah, we walk. We walk as, I mean it’s the months’ been awful for walking. It’s either been too hot or too wet (*too wet yes*) or too cold. Um, but no we do, we do walk a lot, quite a lot. I don’t know whether you know this village at all (*not too well),* but there’s the most beautiful church with a wooden tower that goes back to Norman times and, um, my son’s christened there; um, my, he was married there; my two grandchildren were both christened there so – its just a walk across the fields. So (*you walk)* we walk up there.

**Interviewer:**

***You think that’s helpful, walking?***

**Answer:**

Well, it is helpful and (wife) I’m ..on (wife) again, I’m putting on to her, everything, um, she is very encouraging about the walking. Um, and feels that it’s an essential thing that we should do. But we’re not great socialisers, you know, we don’t, we don’t. (wife) has a good social life, I don’t have a social life, um, but that doesn’t worry me.

**Interviewer:**

***Is that how it’s always been or has that changed because of Parkinson’s?***

**Answer:**

No, that’s probably how it’s always been (*okay),* because I, I’ve always worked for Companies, um, and had colleagues, and met with colleagues well you know what it’s like (yes). Um, and some former colleagues I still keep a contact with, and we meet up, now and again, not that we’ve been allowed to in the last couple of years. I think we’ve done it once in the last couple of years, but hopefully with things coming, well I was going to say coming to an end.

I don’t think that (giggle), I don’t think it’s going to come to an end, it’s it’s, I think it’s still open-ended. I think there’s so much we still don’t know (*absolutely);* we still don’t understand. *(yes absolutely)* Um, and that concerns, that concerns me. Cos (wife), when you get to talk to (wife), you’ll find that she’s got very strong views, you know, about, um, ‘oh it’s all going to be back to normal on the 21st July’, or whatever.

**Interviewer:**

***Well I suppose, you talked a little bit about monitoring and writing down, and writing down your notes and things like that, um, do you monitor your Parkinson’s?***

**Answer:**

In what sense?

**Interviewer:**

***In whatever sense you feel that you’ve had to look after your Parkinson’s. do you monitor your symptoms; or your medications; and how it responds or anything like that?***

**Answer:**

Not really. I mean there’s, I just don’t think I’m not convinced that the drugs .. regime I am on is doing anything.

**Interviewer:**

***And have you spoken to anyone about your concerns about the medications?***

**Answer:**

No, I haven’t. I haven’t, um, because I’ve never discussed it with me GP, ever since he made the first referral. Um,

**Interviewer:**

***Can I ask why not or?***

**Answer:**

I think he’s been too busy. You know, as you all, you all have, you know, you’ve been rushed off your feet, haven’t you?

**Interviewer:**

***But I think GPs, and everyone is still there for everybody if needed.***

**Answer:**

It’s probably another weakness of mine that I’ve not done anything about it. Um, I mean I get on very well with the people in the Surgery, especially with the Dispensary. Um, they know me well, I know them well. Um, they’re always very encouraging and helpful. Um, but I, I think (wife) and I decided that when we see *(PD nurse)* next week one of the things I’m going to suggest is that maybe I have a go at this, um, Mirtazapine … But again, in my past life, which is complicated, in my past life I’ve involved in the launch of several anti-depressants *(I’m sure, yes*). Um, I mean, I talked about the Gastro side, um, and I really hit gold with that cos I was with Lansoprazole. I mean I launched Lansoprazole (a*mazing*) and was making millions. I wasn’t personally making millions, but the company was (*the company was I’m sure*). Yeah, but also over the years, going back to the early days, so this is the early 70s, I was with Rucell and launched Trazadone, Molipaxin. Um, then later on I launched Venlafaxine.

**Interviewer:**

***You’re very used to Antidepressants.***

**Answer:**

So, I’m used to it and it’s crazy because, all the work that I was doing 30-40 years ago, the same people are coming up with the same information today. The same data, today, that they were 30-40 years ago. You know, dear old (name) I mean he; he’s been preaching the same Gospel for ever.

**Interviewer:**

**And how do you feel about starting a new medication perhaps, or thinking about it at least?**

**Answer:**

Very positive. Very positive if, if, as *(PD nurse)* was saying, in her letter um, let’s see I’ve got it here, no I can’t find it. (*no that’s alright)* easily.

**Interviewer:**

***And how, what are your thoughts about how your care has been co-ordinated between, you know, your Surgery; (PD nurse); The Parkinson’s Clinic and anyone else that you see for your health?***

**Answer:**

Well, I think totally reliant upon *(PD nurse)* and the Elderly Care Group. I’ve not involved Primary Care at all. Now perhaps that might be a mistake.

**Interviewer:**

***Well how have you found that the care has been communicated between services if you’ve had any experiences of it?***

**Answer:**

Um, well I’ve just gone along with what’s been said, you know. I’ll give you an appointment in 6 months’ time. Um, if that’s the way it’s gotta be, that’s the way it’s got to be.

**Interviewer:**

***And I suppose just thinking about, you know, whether you think the Healthcare System could be changed to help you manage your health with Parkinson’s?***

**Answer:**

I probably would be more inquisitive. It’s a, I’ve gotta own it if you like. I don’t think other people can own it, does that make sense?

**Interviewer:**

***Yeah, yeah, I think you probably feel like you have to do more for your health, you’re saying, is that right or?***

**Answer:**

Yeah, yes, yeah. But you see the thing is, I’m not, I don’t socialise; I don’t go out drinking and meeting people and perhaps I should do a bit more. Actually, that was one question I did ask, and I can’t remember whether it was *(PD nurse)*, no it was *(PD specialist)* actually. Um, does Alcohol have an effect? Because I liken it to those, you know, those very old black and white films where people sort of wander around in a drunken state. I mean, not that I walk round in a drunken state, but I, I, I feel in a way that I, that’s the appearance I give.

**Interviewer:**

***Right, because of your Parkinson’s?***

**Answer;**

Yeah, it’s got a label. Yeah, Parkinson’s has got a label and it frightens me to death (*of course, yes*). You know, from what I understand it’s a chronic disease; no one understands; there is no known reason for it and yeah, frankly it frightens me. (of course) And you know there’s no magic bullet (*no)*. We’re all looking for a magic bullet.

**Interviewer:**

***We are, yeah. And I suppose, you know, do you have help from anyone such as family, your friends, I know (wife) helps you with your Parkinson’s, um?***

**Answer:**

Well (wife) is the bri, absolute brick. She’s, she’s the one who keeps me in line if you like. Um, I have a son who is in his mid-40s, um, who I know worries about me a lot and I try not. I suppose a lot of time, I put on an act, you know, he says ‘how are you dad?’ ‘Oh, fine, no problem’, you know. But then he’s got his own concerns to worry about; to think about; to concentrate on.

**Interviewer:**

***And what does, you know what does (wife) help you with, with your Parkinson’s?***

**Answer:**

Um, well apart from annoying me by saying ‘what’s worrying you’; ‘why don’t you do this;’ why don’t you do that;’ ‘why don’t you do something else;’ um, she keeps an eye on me. She’s very protective, I mean if it wasn’t for her I would have missed umpteen doses of taking tablets.

**Interviewer:**

***So, she reminds you does she?***

**Answer:**

Yes, she reminds me all the time. ‘Have you taken your tablet? Isn’t it time you took your tablet?’ Yes, no, she’s she’s great, she’s so supportive. We couldn’t have kept it going for 55 years (absolutely) if she hadn’t been, or I hadn’t, you know. You work as one.

**Interviewer;**

***And does she help you with anything else, other than medications for your Parkinson’s?***

**Answer:**

Err, not other than banging on about it all the time.

**Interviewer:**

***And as we’ve sort of talked about, obviously, how Parkinson’s has impacted you and what you do, such as the medications; appointments; going for walks and all of that. Is there anything else you think you’d like to add about, you know, how you look after your Parkinson’s and how you’ve experienced it?***

**Answer:**

Yeah, I just wished there was a tablet I could take that would sort it.

**Interviewer:**

***I think that’s, that’s the dream.***

**Answer:**

It is a dream, I know. And I’ve been too close to things over the years to realise that these sorts of dreams don’t, are not the reality. And I feel, with you for example, I feel I’m providing you with anything.

**Interviewer:**

***No, no, all your information that you’ve given me has been very helpful. Just trying to learn your experiences, um, and how that can help other people, and even yourself, in the future so that’s* *good.***

**Answer:**

I just don’t want to waste your time. Cos your time is so precious to you and to the Community that you serve, you know.

**Interviewer:**

***I must admit you’re not wasting our time at all, in fact, we’re probably taking, I’m probably taking up your time today, um, so, there’s nothing else to add that’s been very helpful um (name). Um, unless you’ve got anything else you’d like to add at the moment.***

**Answer:**

No, I just hope I haven’t wasted your time.

**Interviewer:**

***No, not at all.***