# Interview P04\_070721

|  |
| --- |
| * Length of diagnosis – 10 years * Takes medications 13 times a day, sets alarm * Husband main carer * Faith and religion important here |

**Interviewer:**

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

**Answer:**

I’ve been diagnosed 10 years, but I know I had it for 2 years before that because I suddenly couldn’t play my Flute and Piano where I needed to put the chords down, it was in the wrong place. And the Bass was the last to go, then … So, 12 years altogether.

**Interviewer:**

***And how long did it take to be diagnosed?***

**Answer:**

Well, there was somebody at church, that was a Doctor, and he said, ‘and I know I shouldn’t say this, have you noticed that there’s something wrong with (name)’. And (husband), he had sort of noticed, not a lot. And, um, forgotten what I was going to say. Anyway, I was a bit annoyed, I suppose, and then I thought about it and I wrote down everything that was wrong and, I said to (husband) I’m not going to the Doctors until I’ve got a list of what’s wrong. And that’s what we did. And the Doctor, he’s not there now, he moved down to Cornwall. Um, he got it straight away. And he didn’t tell me what he thought it was, he just said I’ll send you to the Consultant. And he sent me to the Consultant. We went private to start with, and *(PD specialist)* told me what he thought. What I thought was it was either, MS or Parkinson’s or Motor Neurone Disease and I prayed that it would be Parkinson’s cos I couldn’t cope with either of the other two. We’re Bible believing Christians by the way. And err, the Lord answered my prayers, and it was Parkinson’s.

**Interviewer:**

***And, did, how did you get information about Parkinson’s at the time?***

**Answer:**

I don’t remember. I was probably given information from *(PD nurse)* or *(PD specialist)* or something. I have the magazine, which comes, and there’s some interesting things in there.

**Interviewer:**

***What magazine is that, the?***

**Answer:**

It’s the Parkinson’s

**Interviewer:**

***UK one, Parkinson’s UK, yeah, okay. And how do you find, you know, do you want to get more information about Parkinson’s or do you come and take what’s been given to you. How, what’s your preferences with them?***

**Answer:**

Well, I’m not very good at reading magazines and things. But I am interested in different things like, there was some help with taking tablets, um, using fizzy water instead of plain that was quite interesting, and it really helped. And, there was another couple of things, which I can’t remember.

**Interviewer:**

***And was this in the magazine?***

**Answer:**

Yes. Oh, one thing I found out that *(PD specialist)* gave a prescription for um, another pill to have in the night. When I go to the loo sometimes I freeze and (name) can’t move me, so, I keep forgetting what I was going to say. (*your prescriptions).* Yeah, that’s right. They gave me this tablet, I can’t remember what’s it’s called, I can find out if you want to know. At, yes, I found out that if you use a straw it’s much easier to get it down quickly and you get the bottom half which is the bit that you really want to have. So that was good.

**Interviewer:**

***And how did you find that out?***

**Answer:**

I just thought about it. *(trial and error)* yeah.

**Interviewer:**

***And how have you managed your medications with Parkinson’s?***

**Answer:**

Um, I can manage my own, but whoever gets to bed first can. He sometimes puts it all out for me, we’ve got big box and he puts it in there.

**Interviewer:**

***So, what do you have to do to take your medications?***

**Answer:**

Well, we’ve got a list. I could get it for you.

**Interviewer:**

***If you wouldn’t mind, we could get it at the end that would be easier.***

**Answer:**

That’s the right one there (oh thank you). Oh, those are old things; that’s the time I have them.

**Interviewer:**

***Oh right, so you take them 1,2,3,4,5,6,7,8,9,10,11,12,13. There’s 13 different times of the day that you take the medications?***

**Answer:**

Yes (*oh wow).* It’s all on here.

**Interviewer:**

***So, 1,2,3,4,5,6,7,8***

**Answer:**

I should have put all this ready for you. (*no, no, no worries*) Are you familiar with all those drugs?

**Interviewer:**

***Yes. So that’s about 6 different tablets on here. Oh, and you set an alarm?***

**Answer:**

The alarm comes on.

**Interviewer:**

***Oh yes, so, 13 times so that reminds you.***

**Answer:**

The trouble is, I go and switch it off and then I forget.

**Interviewer:**

***Yes, so, how did you, how did you come up with, you know, this routine of medications. How, is this something***

**Answer:**

(husband) did that for me.

**Interviewer:**

***Okay, yeah. And is this something that you found, um, works for you?***

**Answer:**

Well it very important to take the tablet on time, though I sometimes do forget. And with it, it’s, it really is truly important, it is really important. What did you ask me?

**Interviewer:**

***How did you, how did it come about, obviously taking it at different times cos its about 13 times here a day that you’re taking medications. Um, how do you find that?***

**Answer:**

It can get tiresome sometimes. But then I say to myself ‘no, you must be grateful you can have all this medication cos people abroad haven’t got it’. I am grateful.

**Interviewer:**

***And, um, how do you get your prescriptions?***

**Answer:**

Oh, well, they do it electronically.

**Interviewer:**

***Okay. At the Pharmacy?***

**Answer:**

The Doctors here does it to the Pharmacy and the Pharmacy delivers it.

**Interviewer:**

***And that’s quite easy?***

**Answer:**

Well I don’t have to do anything.

**Interviewer:**

***So, how do you find the medications?***

**Answer:**

The first time I had the medication, it really upset me cos I’ve got a Hiatus Hernia. And it got sorted out by the Doctors and, I don’t think *(PD specialist)’*s changed them very much he’s just added some. I find them okay.

**Interviewer:**

***And do you notice if you haven’t taken them, or you’re slightly late in taking them?***

**Answer:**

Yes, I feel really, got no energy.

**Interviewer:**

***And, I suppose thinking about everything else that you do for your Parkinson’s, other than the medications. Are there aspects that you find difficult or challenging?***

**Answer:**

Well life’s not the same.

**Interviewer:**

***In what way?***

**Answer:**

Well I can’t go for walks. I’ve got a wheeler thing, and I can go round the Estate and to the Doctors. We used to love to go for long walks along the cliff tops, and that’s out. But you accept it, don’t you? Otherwise life’s miserable.

**Interviewer:**

***And what about going to appointments.***

**Answer:**

Well usually we ring up if there’s, cos of with all the problems, you just ring up. Otherwise (husband) takes me in the car, cos I’ve had some falls and damaged the skin on my hands so had to be taken.

**Interviewer:**

***And how do you find going to the appointments?***

**Answer:**

In what way?

**Interviewer:**

***Is it easy or difficult getting there?***

**Answer:**

It’s easy. The car’s just outside here. And I can manage it holding onto (husband).

**Interviewer:**

***And um, how many times have you seen your GP about your Parkinson’s in the last 12 months or so?***

**Answer:**

Well because of the pandemic, the first time I went it’s been, a long time was about twice or three times. They don’t, they’re regular, every 6 months I see *(PD specialist)*. I’ve always seen him I’ve been very blessed; he seems to take an interest in my case (giggle)

**Interviewer:**

***And appointments with (PD specialist), how do you find them?***

**Answer:**

He sends me one every 6 months, cos it was longer with (*Covid*) yes. Um, he’s very good. What we do is, we always go in together cos we can prompt one another. We always write down what we want to ask him, cos there’s only limited time. But he wanted us to swap back from the private to the National Health cos he says, ‘you get looked after and chased up if you haven’t been’.

**Interviewer:**

***And, you know, do you monitor your Parkinson’s?***

**Answer:**

In what way?

**Interviewer:**

***Do you monitor your symptoms; how you respond to your medication or anything else you can think of***

**Answer:**

Not really. I take Blood Pressure occasionally.

**Interviewer:**

***You take your Blood Pressure. What, what’s that for, your Blood Pressure?***

**Answer:**

I don’t know what it should be, but (husband) does. (giggle)

**Interviewer:**

***And who asked you to monitor your Blood Pressure?***

**Answer:**

Oh, *(PD specialist)* sometimes asks me, cos I’ve had low Blood Pressure. And then he put me on that, um, Midodrine, and its been so much better. I used to pass out quite a bit.

**Interviewer:**

***And, um, I suppose, have you had contact with other Healthcare Services – so physio, occupational therapists, you know***

**Answer:**

Yes, I’ve been up to, where we met you, the Hospital up there (*local hospital)*. And I’ve been on 2 courses I think. One was for falls; balancing and they gave me lots of exercises to do. You start off well but then then they wear you out so much, you can’t, there’s just too much to do.

**Interviewer:**

***Is this the exercises (yeah)? Are they for you to do at home?***

**Answer:**

Yeah. I’ve been to something up at *(local hospital)*, but it was 1:1 with the physio. And I know *(PD specialist)* has just put me down for some more physio because I’m a bit lopsided when I walk. And I haven’t heard anything yet.

**Interviewer:**

***You haven’t heard anything yet?***

**Answer:**

No. I must really try and do some exercises. But they wear you out that’s the problem. and you get tired enough with Parkinson’s.

**Interviewer:**

***Yeah, yeah. but do you, so even though you feel tired with Parkinson’s do you, do you do your exercises if needed?***

**Answer:**

No. I must be honest

**Interviewer:**

***Absolutely, yes. And, and what do you think, you know, do you find physios helpful or the exercise sheets that they give you helpful?***

**Answer:**

Well, I haven’t been doing them long enough to say they make a difference.

**Interviewer:**

***Um okay. And have you had any issues about getting help at the weekends or out-of-hours if needed?***

**Answer:**

I don’t think so. Well there’s different, haven’t they, other than Parkinson’s I haven’t had much problem with illness.

**Interviewer:**

***You don’t have any other medical conditions other than your Parkinson’s?***

**Answer:**

But I, I decided I’ve got Asthma. Uh, no not really.

**Interviewer:**

***And have you had any financial expenses associated with managing your Parkinson’s?***

**Answer:**

No, very blessed.

**Interviewer:**

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

**Answer:**

Well, we have had in the past, cos you learn, there’s a lot to learn at the beginning. And *(PD nurse)* has been very helpful.

**Interviewer:**

***And (PD nurse) is the Nurse Specialist there is she?***

**Answer:**

Yes. Have you not met her?

**Interviewer:**

***Yes, I have met her once I think, yes, yeah. In which, in what way is she helpful?***

**Answer:**

Well she solved whatever problem it was, but I can’t remember what it was.

**Interviewer:**

***And you said there was a lot to learn when you have Parkinson’s***

**Answer:**

Yes, but they don’t give it you all at once thankfully.

**Interviewer:**

***So, they prefer that they don’t give you all the information?***

**Answer:**

In one way it would be helpful. And I got, well, Cystitis and landed up in Hospital because I didn’t have the medication for it. If I’d known about that, I’d probably have saved myself a trip to Hospital. And same with constipation I, ended up in Hospital cos I got a small blockage. And if I’d known about that, that wouldn’t, I would have not ended up in Hospital.

**Interviewer:**

***Yeah, yeah. So, was it after that you learnt about it, after you went to Hospital?***

**Answer:**

Yeah. and so, since then it’s been so much better.

**Interviewer:**

***So, you’ve made sure that you don’t get constipated, to try and prevent the same problem? (Yes). And where did you learn about them, was it while you were in hospital? (yes) And how were your experiences in Hospital?***

**Answer:**

Wonderful. (*good to know, yeah)* the food was really nice, that’s what I like. And they were amazing.

**Interviewer:**

***Good, yeah. and do you have to monitor your diet with Parkinson’s or change your diet for Parkinson’s?***

**Answer:**

Well I think we have quite a sensible diet anyway. We don’t drink or smoke. We don’t eat fancy things; we like salads and fruit and vegetables. Though we do have quite a few cooked meals, ready cooked meals because sometimes that day we will have one because we will be tired. (husband) does most of the cooking, and he’s got various problems; a neck problem; a back problem and he won’t feel like cooking, a cooked meal so we, about once a week,

**Interviewer:**

***And how do you feel, um, you care, and what’s your thoughts about how your care has been co-ordinated between the different Services after all these years with Parkinson’s?***

**Answer:**

I’m not sure I understand what you mean.

**Interviewer:**

***So, in terms of your Surgery; and (PD specialist), and (PD nurse) and, you know, your physiotherapy. Do you think your care’s co-ordinated well or not so well?***

**Answer:**

Yes, don’t see anything wrong with it. *(PD specialist)* is amazing.

**Interviewer:**

***That’s good. And, I suppose what, what things or what has helped you manage, you know, your Parkinson’s so far?***

**Answer:**

Having a husband who’s very understanding and who will go sort of through it with me. And being a Christian because I can pray about things.

**Interviewer:**

***Having your faith and religion is helpful?***

**Answer:**

Yes, I couldn’t manage without it.

**Interviewer:**

***Um good. And, I suppose (husband) helps you out most of the times then. Anyone else who helps your or?***

**Answer:**

Oh yes, I have 6 hours a week. Lady come in does all, I don’t do cleaning, couldn’t do it, too tiring. Um, she keeps the place nice; she does all my ironing and she does some shopping. We have online shopping for the bulk of it once every 4 weeks, and then she does, like twice a week, gets the milk and the fresh vegetables and things.

**Interviewer:**

***And how did you find out about her and getting help from***

**Answer:**

She goes to another Church I think you know from that. I can’t remember exactly.

**Interviewer:**

***And do you have any paid Carers that help you with personal care?***

**Answer:**

No, they’re all paid. I get an allowance from the Government, what’s it’s called, Attendance Allowance but it doesn’t cover it, anywhere like, but I’m not complaining I’m grateful for what I do have.

**Interviewer:**

***And that, that pays for the Carer that comes in to help you?***

**Answer:**

It pays toward it.

**Interviewer:**

***And how did you, you know, how easy or difficult was it to organise?***

**Answer:**

Difficult to remember, but (husband) will remember.

**Interviewer:**

***And are you aware of where to get information, if you needed to get more information about getting help?***

**Answer:**

I haven’t really thought about it cos it hasn’t cropped up.

**Interviewer:**

***Okay, yeah, so you haven’t thought about it. And I suppose, can you think of ways that the Healthcare System can change to try and help you manage your Parkinson’s?***

**Answer:**

Ah, that’s a difficult one. Not off hand I can’t. It’s more difficult for other people who haven’t got a husband to help them.

**Interviewer:**

***And do you feel overstretched with everything you do for your Parkinson’s?***

**Answer:**

Well nights are a problem. I don’t remember anything that goes on in the night.

**Interviewer:**

***In what way are you saying that nights are a problem?***

**Answer:**

Well (husband) tries to wake me up to go to the loo, and sometimes he sleeps through the alarm cos he’s tired. But we’ve got it worked out with the pads and the pants and everything. But it’s not, not very nice.

**Interviewer:**

***What time does he set the alarm?***

**Answer:**

I think the first one is about an hour and a half afterwards.

**Interviewer:**

***After you go to bed?***

**Answer:**

Yeah (okay). We’re not good at going to bed early. We seem to wake up and its time to get up (giggle). I think sometimes the evenings are my best times, mornings the worst.

**Interviewer:**

***In what way?***

**Answer:**

Well I get tired very easily, and I’m so slow (interesting). All the mornings, after I’ve had my breakfast. I have my breakfast first and then get up. And just takes me a long time.

**Interviewer:**

***And that’s despite taking the medication?***

**Answer:**

Yes. And I slow down.

**Interviewer:**

***Slow down since you’ve taken the medication or slowed down since?***

**Answer:**

No, not since I’ve had the medication cos I’ve had the medication from the beginning. Um, I think in the last 6 months or a year, ask (husband) those questions.

**Interviewer:**

***And you know you said the middle of the nights, about the pants and the thing, how did that come about?***

**Answer:**

Yes, you find out really. We’ve got a commode. The Hospital they, or the NHS, are very good at providing everything you need. Cos I’ve got a stool; I can sit at the basin if I don’t feel like standing up. And I’ve got a commode; they’re not very comfortable.

**Interviewer:**

***No. and that’s for the middle of the night when you wake up?***

**Answer:**

Yes. I don’t wake up; (husband) usually wakes me up. Some, occasionally I’ll wake up.

**Interviewer:**

***And is the water problems because of your Parkinson’s?***

**Answer:**

Yes.

**Interviewer:**

***And how long have you had that for?***

**Answer:**

Um, it’s a job to remember. At least a year I should think.

**Interviewer:**

***And what’s the most troublesome, or the most difficult thing that you do that you have to do to manage your Parkinson’s?***

**Answer:**

I don’t know really.

**Interviewer:**

***Hard to say?***

**Answer:**

Yes. I mean all of its not very nice, but you put up with it don’t you?

**Interviewer:**

***Yes, but when you say, ‘all of it’, remind me, what do you mean by ‘all of it’ from your point of view?***

**Answer:**

Well having Parkinson’s. *(so just*) Cos, (husband) retired and since he retired I was diagnosed with Parkinson’s so all the things we planned to do, and all the things we hoped to do, were forgotten about. But we’ve done other things. We belong to the Harmonica Society, I don’t play the Harmonica, but I play the piano so I can play for (Husband) while he plays his Harmonica. So, we’ve got music in the place again which is nice. We used to, I used to play piano, or I’d play all my instruments at different times but I used to play the Piano in the Church Music Group and (husband) used to lead, he’d play the Guitar. All that went. But we can look back on those memories.

**Interviewer:**

***Of course. And how was, you know, I suppose, how has Parkinson’s impacted your life and social networks as a whole?***

**Answer:**

I’m not sure that I understand what you mean. We don’t have, I don’t do much in, um, well I can send e-mails and I’ve got an iPad but I’m not very well with the computer. You mean like, um,

**Interviewer:**

***I mean about, you know, about your medications, and the timings of your medications. Does that impact your day to day activities and what you would do?***

**Answer:**

Yes. We, the first tablet I take is twenty to eight. I have to make sure that the alarm goes off and I take it, cos that’s it, Omepr, can you see it on the (*Omeprazole*) yes (*yes).* And that really works very well, cos in the past I’ve had tablets and haven’t had the Omeprazole and it hasn’t been so good but that seems to last me the whole day and cover all the tablets I have. Yes, and we have to have things at certain times, medication. It will go off at 3 o’clock. Yes, it stops you doing things. I mean I’m no good at stairs and if you go to somebody’s you have to say to them ‘have you got a downstairs loo’. Most people do have these days, but I bit embarrassing. Most people understand and some don’t. Did you ask me a question and I haven’t answered it?

**Interviewer:**

***No, no, just seeing if you have any more thoughts, but it seems that, I suppose you, a lot of things that you do for your Parkinson’s, you know, you’ve done for many years. Um, and, accept that into your life every day I suppose with Parkinson’s.***

**Answer:**

I think it is a good thing if you can accept it. My brother has got Parkinson’s, but he has got. He had a stroke and then got Parkinson’s do you know what that one’s called?

**Interviewer:**

***Probably Vascular Parkinson’s***

**Answer:**

Yes, that’s right. That’s what he’s got. And, he’s not doing very well. he can hardly walk; he won’t take the tablets. He says they don’t do him any good. It doesn’t make any difference, but it must do surely. Anyway, I’m going to write to him and encourage him to take them for one month just to see if they make a difference.

**Interviewer:**

***Is there anything else that you’d like to add that, you know, thinking about the things that you do to help with your, to manage your Parkinson’s that we haven’t covered. We talked about, you know, medications and appointments and how you manage your medications with the iPad and your checklist here. Um, so anything else that you think you do for your Parkinson’s that we haven’t covered.***

**Answer:**

You’ll probably get a lot more out of (husband) if you ask him any questions cos my memory’s not what it should be. Short term memory’s not very good. I think the good thing was I accepted it from the beginning cos I knew there was something wrong and, with the Lord’s help I was able to knuckle to and sort myself out and make the most of it. (husband) has been a great help, but my brother is in denial I think, which is such a shame.

**Interviewer:**

***Well if you haven’t got anything else to add then thank you very much for your time. That was very helpful.***

**Answer:**

It was a pleasure.