# Interview C01\_290621

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| * Length of diagnosis – less than 1 year * Although noticed symptoms earlier * Always takes medications outside just in case |

**Interviewer:**

***So, you know, suppose I will start by, you know, asking a few general questions about (name) who has Parkinson’s and, how long has it been, and how did you find the diagnosis of Parkinson’s?***

**Answer:**

Well you know thinking back, cos I think it was actually, was it 2 years ago, um, but before that there were one or two things, when I look back now, and I think ‘oh maybe that was what it was, it was started’. We’d had um, I don’t know whether my husband said, had a really difficult 4 years. Um, and then we’d, cos it was with my mother, she was 100, but when she was 99 she broke her arm. She lived independently in *(city name)*, so we were having to go up and down, up and down every week-end, um, plus I’ve got a business as well, and, and we look after grandchildren as well and we’ve got quite a lot of work here as you see.

Um, and that sort of took its toll I think, and we also sold, we had a cottage which we’d had for 35 years near *(town name)* and um, the, the removal date was actually about 2 weeks before my mother died. And you could imagine having had it for that length of time, so much stuff. But what I was going to say was, when we got back; we got back very late after the removal men moved in, and we went upstairs absolutely shattered, you know, stuff everywhere, and (husband) fell. It just sort of came out of the blue and we thought he’d sort of tripped on a strap from, you know, one of the cases, um, but he hurt himself quite badly. Cos he fell into a sort of corner by a chest of drawers and a chair, and whipped his arm on the metal (yes, yes he did say that). did he say that? (*yes, he did, yeah).* Um, and at the time I just thought, well we were so tired, and you know it was just one of those things, but when I look back I think ‘was that the start?’ And there were one or two others when he was hedging and fell off the ladder.

There were just sort of one or two things, at the time didn’t think about it, just thinking it was, you know, we were tired and stressed out, but maybe that was. That was back in, when was that, 2016, 2017, 2017. Um and then yes, was it last year or the year before that he was diagnosed, oh the time goes doesn’t it. Um, and I think I realised there was something not quite right, and I had in my mind thinking it maybe that. Um, so I suppose in a way I wasn’t surprised, um, and I felt quite confident after talking to *(PD specialist)* about it, um, thinking it would be able to be controlled for quite a while on medication. But the last few weeks he hasn’t seemed so good, and I started to get quite worried really, about the future and you know, where we’d live; how we would handle everything.

**Interviewer:**

***I suppose going back slightly to, how long did it take for him to be diagnosed after that, I suppose* *you’ve noticed that and meeting (PD specialist) for the first time. How long did all that take?***

**Answer:**

Before we saw her I s’pose a year maybe. It’s funny, actually, because I hadn’t sort of realised but it was the chap who helps us in the garden, and um, was it last summer or the summer before, he said to me ‘is (name) alright?’ And um, I said ‘yeah, fine’, and he said ‘we’ve just noticed the difference in him’. And I think I hadn’t really noticed it myself then, but gradually, yes I was noticing certain, just certain things, yes, yes.

**Interviewer:**

***And how has it been getting information about Parkinson’s***

**Answer:**

Well, um, not good at all really. I think because of Covid as well, we haven’t really been able, we haven’t really, no, we haven’t sort of found out anything about it. Um, we had wondered whether, cos I thought exercise was meant to be quite good. And I mean we actually did walk quite a lot; we do walk a lot but somehow or other the last sort of 4 months we haven’t because I think we’ve had so much in the garden to do; weather hasn’t been brilliant has it, on and off. Um but I always thought he was so much better after. We walked miles in the country, and he seemed so much better; he seems worse when he’s actually in the house. He seems to sort of shuffle and, not, he has got very shaky, and I, um, noticed that the um, little things. Well the first thing that I noticed, which was about a year ago, when he was doing the pressure on the tyres. He thought the machine had gone wrong, and at the time I didn’t realise then, but I now realise that he didn’t have the perhaps the strength to really do it, to push hard, yes.

**Interviewer:**

***And I suppose you, you said you hadn’t any information, have you?***

**Answer:**

No, we haven’t, no. I mean I just sort of looked up, googled it you know, to try and find out a bit. Looked at, thought I’d go to the Library and find out. Um, but I mean I had a couple of friends whose husbands had it, but they didn’t actually say a lot about it.

**Interviewer:**

***And how did you find Googling, or going to the Library was that helpful?***

**Answer:**

Um, yes, well yes it was sort of helpful. I learnt a bit more about it; that there was sort of stages. Um, and I can quite, I can see that is (husband), that it is. It’s very slow isn’t it, (*yes it is*) cos it is, just gradually I noticed the changes.

**Interviewer:**

***And was the information easy or difficult to understand?***

**Answer:**

No, it was quite easy to understand, yes, yes. I think the first thing with (husband) was the shaky hand. Um, cos when you’re sort of coming up the stairs with coffees in the morning and it sort of just gradually got worse, I think that probably was the, one of the first things apart from the falls, yeah.

**Interviewer:**

***And obviously, they seem to start medications for his Parkinson’s and***

**Answer:**

Yes, well I, I thought that had made a difference but (husband) didn’t think it had terribly.

**Interviewer:**

***So, you’ve noticed a difference have you?***

**Answer:**

I had. But I’ve got to the stage now that I’m wondering does he need something a bit stronger or a bit more each day or something. So, I’ve listened to some man talking, he was saying he was on 4 times a day I think, and he said he knew when it was time to take it because his, he got really, really shaky. Um, I’ve, with (husband) I’ve noticed that when he gets tired, like the late afternoon, that’s sort of the worst time, and then if we’ve, cos sometimes we forget, um, to now we’ve sort of got organised and I keep some in my bag when we’re out, and then I noticed once had the tablet, after an hour, he’s um, well if we get back; I leave him for half an hour sitting down watching TV and he’s different again.

**Interviewer:**

***Um, so do you help him with his medications?***

**Answer:**

I, um, try to remind him yes (giggle). *(and do you*) He’s not very good at remembering.

**Interviewer:**

***Yes, yes, and how do you remind him. Do you use anything to help you?***

**Answer:**

Well in the morning he always takes it; cos he always comes down early to make a cup of tea, so he does them. Lunchtime he will forget so, when we have lunch I always put it out, then sometimes I put it out, but he still doesn’t pick it up. And the evening one, the evening one is the one he tends to forget

**Interviewer:**

***So, you take some with you in your bag***

**Answer:**

I always take, I always keep some in my wallet now, spares, yes, I’ve got them.

**Interviewer:**

***Is that cos you’ve missed doses before or is it just in case?***

**Answer:**

Well, before, one day we went to watch our grandson in a, at a cricket match; it was all sort of rather rushed; I was frantically trying to get a picnic together; had in my mind I must get the tablets; forgot them; and he hadn’t taken one so he actually went all day, and he, by the time, he wasn’t very good by the evening. He, um, so no he seems to get like in a sort of zone, you can’t sort of get through to him. Um, but there again once we got back; he took the tablet and seemed better again.

**Interviewer:**

***So, you monitor his symptoms and you’ve noticed how his Parkinson’s has progressed or?***

**Answer:**

I feel it has progressed a bit. I was rather shattered actually, because at the beginning I thought, it, we were sort of managing quite well. Um, and I kept thinking is it because we haven’t had a lot of exercise? I mean he hasn’t been, does that make a difference or?

**Interviewer:**

***Yeah I mean exercise is a good thing in people with Parkinson’s. (Is it) Um, so yeah generally we’ve found, studies have found that has been very helpful. Um, but obviously some people may not notice a difference or might find it difficult. What sort of exercises do you, exercise do you do, walking?***

**Answer:**

Well, because actually our son had a dog, but sadly he was unwell and we, he had to be put down, but we had, we’ve always had dogs ourselves. So, when we looked after him, then obviously we had to walk as it was a Dalmatian and yes, but we still enjoy walking, you know, but it’s walking through fields; woods and we do enjoy that, yeah. Um, but also (husband) had, well he has been terribly active and with the garden he has an awful lot of work here, but I think he’s finding that difficult now with the hedges. The hedge trimmers got heavy, and um, so I said, ‘you’ll just have to, if he feels like doing it just do a bit at a time’. Bit of a hedge and leave it, yes, yes so that’s what we’ve been doing really. He does get tired.

**Interviewer:**

***Yeah, so that’s what you’ve noticed is the tiredness***

**Answer:**

It is the tiredness yes. He says it’s a different sort of, it’s like an exhaustion really.

**Interviewer:**

***Yeah, okay. And in terms of all the appointments that you’ve had, and seeing (PD nurse) and others, how have you found any of the Healthcare Professionals?***

**Answer:**

Yes, um, very. With *(PD nurse)* very helpful actually, I think we’re seeing her next week. Um, cos I said ‘we must ask lots of questions’, cos I don’t think we asked enough questions to start with. I think it’s sort of unnerving, you don’t really know, you know, what’s going to happen. But I have, I have got actually quite worried myself, just lately, cos I sort of panicked about the future and you know how it’s going to be and how would we manage here with him and, yes.

**Interviewer:**

***And do you think having more information would help?***

**Answer:**

I think it would help, yes. (*okay)* I do.

**Interviewer:**

***And I suppose the question is if you need any information, or you had a concern about Parkinson’s, you know, is there someone you would speak to or where would you go to look out for that?***

**Answer:**

That’s a good point. I tend not to, um, I’m quite sort of private. I don’t actually really talk about it with anybody. (name), our son, I think he’s quite concerned about it, but I mean he wanted us to move but, I, I just feel we’ve left it too late really but um.

**Interviewer:**

***And so the appointments have been helpful and***

**Answer:**

Yes, they have. Yes

**Interviewer:**

***In what way, what makes them helpful?***

**Answer:**

Um, well I think with *(PD nurse)*, well she’s very sort of, um, straightforward um, and she just sort of says ‘oh well we can help you with that’. Cos he hasn’t been sleeping at all well, well although he actually, he’s never slept very well but um, I think he does worry about it himself now. I might be wrong but, I think he does cos sometimes he gets quite down and if I say, you know or, ‘what’s the matter’, and he’ll say ‘well I’ve got this progressive disease’, and it sort of sounds a bit dramatic but I think it does play on his mind, um. But I say, well, you know, you’ve got it, so we’ve got to take it sort of day by day really.

**Interviewer:**

***Yes, of course. And what else do you do, or what else does, do you do to help him with his Parkinson’s.***

**Answer:**

Well, we had wondered about Pilates whether that was a good thing. But there again you see we don’t really know whether that would help or whether the walking which we enjoy, appears to help him I thought because I wondered because I felt that he’s deteriorated a bit the last 3 or 4 months, 3 months maybe I thought is is because we haven’t been walking. I don’t know whether that would help, I suppose everyone’s different.

**Interviewer:**

***I suppose knowing whether it would help change the way you approach his Parkinson’s.***

**Answer:**

Yes. I don’t, I don’t know whether, I’m inclined to sort of take it by day and, some days he seems fine and we sort of press on in more or less the same way; try to. Although he can’t, you know, obviously can’t do as much, but otherwise I’ve got an interior business and he comes, helps with that. Um, still does the driving as well, yes, so at the moment,, you know, it’s sort of manageable.

**Interviewer:**

***Yeah, of course. I was thinking about, you know, the Parkinson’s and yourself, how do you think the Parkinson’s has impacted your life and your social networks at all, if it has?***

**Answer:**

Well it’s difficult at the moment because we haven’t really had, because of the um, the virus we haven’t really sort of been mixing so it’s difficult to say. Can’t really tell though. We’ve only just, I think, a couple of weeks ago we did actually go out for lunch but otherwise we haven’t been doing anything, apart from seeing our grandchildren. And that’s sort of work, you know, because we .. take them back; feed them and oh dear, yes. (giggle)

**Interviewer:**

**And I suppose, thinking about yourself and your role, do you think that’s changed since the Parkinson’s?**

**Answer:**

Um, I think maybe I was sort of help him a lot more, than perhaps I used to. Yes, I do think that, yeah

**Interviewer:**

***And, you know, thinking about, you know, all that you do for Parkinson’s are there any aspects that are perhaps more difficult or challenging when helping with the Parkinson’s?***

**Answer:**

What for me helping him? Um, helping him. No, I think, I mean, the things that I find that he finds difficult, getting up and down from a chair; that’s difficult; in and out of bed that seems to be difficult actually for him getting in and out of bed though he manages on his own. Um, and I think he finds it difficult like doing buttons; he doesn’t say anything, but it takes longer. Um, so I don’t actually say ‘shall I do it’, I’ll, I let him just, unless he asks, so obviously then help but otherwise I don’t, no.

**Interviewer:**

***And I suppose, do you feel overstretched with what you do to help him with the Parkinson’s?***

**Answer:**

Um, well I feel there’s a lot more for me to do, yes, I do feel that. sometimes I think ‘gosh, you know, how we going to if he gets worse. How we going to cope’, yes I do. I do worry about that.

**Interviewer:**

***And do you think about ways that can help with that in advance?***

**Answer:**

Well obviously yes I have thought that about, you know, having to have like a bed downstairs; perhaps we should have to do something, we have got a cloakroom thing. And I suppose you know that we’d manage. Friends that I’ve had whose husbands had it, and actually my niece had it, but she had, um, live-in Nurse with her and actually the 2 friends with the. I don’t quite know what it was, they referred to it as a, a type of Parkinson’s they didn’t sort of go into it in detail. Um, but I suppose, yes I have thought about, oh gosh what the, you know, what’s ahead of us. I mean is it for everybody or not, I mean I don’t know.

**Interviewer:**

***Again, it varies with everybody absolutely. And do you know where to get information to look up about … and would it be helpful?***

**Answer:**

I’m sure it would. I think that’s our problem we just don’t understand it, at all. So, I think it would help, so yes.

**Interviewer:**

***And how do you think we can help with helping you, you know, with the information or understanding of Parkinson’s?***

**Answer:**

Tell him what he could experience; what could happen I think. I think it would help to know really. I mean I don’t know whether he would go on as he is for two or three years, or whether he could suddenly get worse. Thinks like that. I know it’s probably difficult to say, everybody’s different I suppose, yeah.

**Interviewer:**

***Yes, I think there is an uncertainty there I think with Parkinson’s. I think you’re right everybody’s (different) different. Um, it’s hard to predict I think.***

**Answer:**

Yes, so you hear some people say ‘oh well I’ve known people they’re perfectly okay; medication they go on 10 years quite alright’. Um, but how, how do we know that? Are there signs that we would know, to tell when it’s getting worse or?

**Interviewer:**

**Do you monitor his Parkinson’s?**

**Answer:**

Um, not really no. I mean, obviously I notice the differ, you know that it, he is progressing a bit, yeah. I do notice that.

**Interviewer:**

***And in terms of, you know, all your experiences with Healthcare so far, I know there’s a little folder there, obviously his Parkinson’s folder as (husband) calls it. How have you found the communication between services and yourselves so far?***

**Answer:**

Yes, very good; very helpful, yeah. Especially Josie I think she’s very good.

**Interviewer:**

***And do you think there’s ways the Healthcare System could be improved to try and help you?***

**Answer:**

Well I think it would have been nice to start with, actually, if we had been given a bit of advice on what could happen and the things to expect. Cos I didn’t know what to expect at all really. So, I think

**Interviewer:**

***So, you said you went on Google, online to***

**Answer:**

I mean yes I did. it’s not a thing I like to do really but I did out of sort of desperation to try and find out a bit about it.

**Interviewer:**

***And was that because you really didn’t, wasn’t, didn’t know about it so you felt you had to out of desperation?***

**Answer:**

I just didn’t know anything about it at all, no, I really didn’t, no.

**Interviewer:**

***So, seeking out information helped with that?***

**Answer:**

Yes, it did, yeah.

**Interviewer:**

***And does, I suppose, the question about yourself, I suppose, do you have any other medical problems. Do you have any medical problems yourself?***

**Answer:**

Touch wood no I don’t. The only thing I do have is an Ectopic heartbeat which I take medication for. But, that’s sort of controlled, but, but it gets out of control in terribly hot weather or it did before I had the medication. And after a lot of exercise, but now touch wood, it’s okay.

**Interviewer:**

***Has it been challenging looking after your health and looking after (husband), or helping him with his health* *or?***

**Answer:**

No touch wood I’ve always been quite, no. if I get sort of really stressed or, I just garden cos I can just lose myself there, in the garden. I do find that helps a lot, yeah. Cos we have got quite a busy life really. Um, cos my business takes up quite a lot; grandchildren do; and the work here. Its quite a difficult house to keep going really (giggle)

**Interviewer:**

***And you know with all that you have to do, how is it looking after your own health and (husband) and everything else?***

**Answer:**

Well I, as I say I do find the gardening, and I have got a group of friends and we always, um, well we haven’t been able to of course, but we always used to go out for lunch once a month and pick different places. And I now meet them for coffee. But also, my business is quite nice cos it’s a social thing as well. so, I find that’s quite

**Interviewer:**

***To have that social network meeting people***

**Answer:**

My release, something I really enjoy and so that sort of helps I think. You see I find it difficult; it’s taken me a long time to get over the death of my mother. Um, at the time we were so busy I don’t think it started to hit me really until last year and unfortunately that was just when (husband) was diagnosed. And so, I did find it quite difficult. I didn’t seek help or anything, I just thought ‘oh well things will bash on and get through it somehow’. But, I started getting um, Migraines and terrible nightmares and I think it was all, you know, you keep going, keep going, keep going cos there were, it was just so awful what with my mother being so ill and going down. And then there were properties to sell; it was the winter; the pipes were freezing, and we had to keep driving to Somerset. It was a nightmare really, a nightmare. And we had terrible problems with my brother as well. Um, so I think I just kept going and then last year it sort of caught up with me, but I’m better now, yeah.

**Interviewer:**

***Quite a lot to handle at one time.***

**Answer:**

It was, it’s the way isn’t it though. Everything always comes at once, yeah.

**Interviewer:**

***Yes, life is funny (giggle)***

**Answer:**

Yes, I know that’s right. It was awful, also I don’t know whether (husband) mentioned my youngest grandson had been ill for a year, and they just didn’t know what was wrong with him. It all started from a virus he had, and he, you know, I used to get so worried about that. So that was on top of that. And then my son also has had various things wrong so, yes it’s one thing after the other really. And then there was (husband), that was the last straw really.

**Interviewer:**

***And well I suppose your coping strategies to try and help with that, what did you find helpful? (yes) so you talked about the gardening and***

**Answer:**

Yes, I do find that I can, yeah.

**Interviewer:**

***And I suppose is there anything else that we haven’t talked about that you help do for (husband’s) Parkinson’s, to help him manage his health that we haven’t quite addressed?***

**Answer:**

I don’t think so. Only I wouldn’t say we’ve done anything differently really. We’ve just sort of gone along. I think perhaps we try not to do as much. We used to, I think do too much and now we try and do like one thing a day and then there’s a lot of sport luckily so encourage him to sit down and watch the sport, which he’s quite happy to do.

**Interviewer:**

**So, planning things (yes). Doing one thing at a time (yes) Has that been helpful?**

**Answer:**

It has. It has because, I mean there’s certain things like if we’re looking after our grandchildren its, we always leave here at lunchtime and we don’t get back until sort of 8ish in the evening. So, I always make sure now that we don’t do anything in the morning, cos if we do it in the morning, we’re tired and then we’re rushing. Rushing seems to be not good at all, he’s much better along calmly

**Interviewer:**

***So, spreading things out***

**Answer:**

Spreading things out, yeah, we definitely do that now *(a change from)* from as we were, yes, definitely.

**Interviewer:**

***And how do you think Covid has had an impact on (husband’s) Parkinson’s or health, how you manage his health?***

**Answer:**

Um, I just feel that he’s just got more worried about himself in the last couple of months. Whereas before he, I don’t think he, he didn’t say much about it he might have done, but I do feel he has worried more, it’s a shame really.

**Interviewer:**

***Is there anything else you’d like to add that I haven’t touched upon?***

**Answer:**

I don’t think so. It’s just, it would be nice to have more information. I think that’s, that’s the thing that we’ve both found. We don’t really understand it and would like to know a bit more. And it’s not easy to know where to go to find it, you know. And I don’t know if there’s Groups that you can meet up. Do they have groups of people?

**Interviewer:**

***Yes, so there are local Support Groups available, um, and the Parkinson’s UK Charity.***

**Answer:**

So how do you find out about local Groups?

**Interviewer:**

***So, the Parkinson’s UK website and I think if you Google Parkinson’s UK they will be able to signpost you to where’s local. (PD nurse) might have some information about the Support Groups here that might be available. (right) do you think that might be helpful, Support Groups?***

**Answer:**

Definitely. Um, for (husband) it would be nice. Well for both of us actually. Cos you sort of listen and see how people are; how they cope with this and I think it would help, yes, yeah, um

**Interviewer:**

***There’s certainly, I don’t know obviously what’s changed with Covid, and what’s running and what’s not running because of Covid***

**Answer:**

I think that’s what’s been the problem, you see, since we found out, nothing, everything’s sort of closed down.

**Interviewer:**

***Yes of course you only found over Covid isn’t easy.***

**Answer:**

Yes, that’s right, it’s been so difficult.

**Interviewer:**

***Yes, and I think some of your appointments have been telephone rather than***

**Answer:**

Yes, they have. I don’t think (husband) likes that at all. I think he prefers the face-to-face.

**Interviewer:**

***And do you go with him to his appointments?***

**Answer:**

Yes, I do.

**Interviewer:**

***So, I suppose the telephone ones are a little bit difficult***

**Answer:**

Yes, yes. Yeah so it hasn’t been easy really with the Covid. So hopefully if we’re coming out of it, it’ll change, yeah.

**Interviewer:**

***And going to his appointments, has that been helpful for you?***

**Answer:**

Yes definitely, um. Oh yes they have. Yes it is nice that he, you know, wants me to go. I didn’t know whether he would want to go on his own; whether it was easier to talk on his own but, no that’s been quite helpful.

**Interviewer:**

***Great. Well if there’s nothing else.***

**Answer:**

No nothing else at all