# Interview with C05\_12072021

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| * Caregiver of PD patient with DBS * 17 years diagnosed with PD * Choose to avoid social care help due to previous experiences * Driving and access to IT |

**Interviewer:**

**So just a few of the questions about (name’s) Parkinson’s. Um, so he said he was diagnosed about 17 years ago. And how did they, how did he get diagnosed, what was your recollection?**

**Answer:**

Well, he thought he had, I think it was Carpal Tunnel at work. He was trying to click the mouse and it wasn’t working properly. Um, and he went to our GP, at the time, (GP name) and she knew. She knew what he had, um, because she sent him straight to the right Consultant. So, she obviously knew. And, shock, when he came home and told me that it was Parkinson’s. I hadn’t really, to me Parkinson‘s was an old person’s disease; I’d never looked into it; I never thought that’s what he had, so it was a big shock, a big shock. And like everything else, it’s not going to make any difference to your life, but it does.

In the first few years not so much, but gradually over time, obviously it has made a big, big difference to us. Um, cheated, feel cheated about what we should have had at our age because (husband) did, well, everything that he wanted to do was taken away from him. And obviously you have to accept it, you can’t change it. Obviously, it is what it is, but, you know, when I look at other people what they can do. I mean at the time, originally, it wasn’t too bad because he wasn’t that bad. Um, so we could, he could still play golf; he could still go to the gym; he could still volunteer up at (Gardens). I carried on doing it, I, I well we both carried on working, but it gradually came to a, obviously (husband) wouldn’t be able to carry on working. And that was a big wrench for (husband), because, although his job was hard, he put a hundred percent into it. And to make that decision, err, and to be told by the Occupational Doctor where he worked, that normally he was desperate to get people back into work, that he was desperate to get (husband) out of work. So, it brought it home to us that, you know, (husband) was going to have to pack up work.

And that was a big, big, well big wrench for him and for me, but his, his acceptance of it is brilliant. I mean we have had days where he gets down and he’ll cry. Um, he thinks he’s useless, and then it’s gone. I’m, I’m very lucky I don’t suffer from any sort of depression or, ah, and I can always, I suppose, look. You know, we sometimes say something, or laugh about something, and you think, ‘yeah, there’s still a bit’, you know. We’ve still got a marriage where we can do that. sometimes I’m so exasperated with him I could murder him (giggle). And then, but, you just have to live with it, live with it. And I’ve tried desperately hard over the years; desperately hard to try and have more patience with the fact that he’s got Parkinson’s. And sometimes, you know, I let rip because I have got a temper. I mean, everybody’ll tell you I’m renowned for a temper. Um, but it’s not at (husband), it’s at the Parkinson’s that riles me, because it’s taken away the things that, you know, that he’s always wanted to do. He’s always done.

The stupid thing is, the other day we had to have a new washing line; when it came it was the wrong diameter to go down the hole. So, (husband) would have done that; he would have dug out a new hole; filled it with concrete and done it. And I had to do it. And, and its things, you know, it’s taken away from him the things that he would have done. Um, luckily, thank God we have a gardener because I can’t garden, I love the garden but don’t enjoy gardening. I haven’t got the time, but he always used to love the garden. The garden was his, and doing things like, you know, looking after the cars; sorting everything out; it’s me now that does it, literally everything.

Sometimes I’m chasing myself round in a circle, you know, trying to do everything, plus look after him. I have a Nurse, private Nurse in the morning to help. But I always get him up. (husband’s) a very private man, um, and he found when I had to take over, when he goes to toilet proper, faeces, I have, I sort him out; clean him up and sort him out. And that upset him greatly. And, you know, I said, ‘(husband), it doesn’t bother me; its, things like that. I’m so lucky that it’s never, you know, some people would say, ‘oh I can’t do that; couldn’t touch him there’. That doesn’t bother me; just get on and do it. But for somebody who’s been very private, like all of us, you know, doing something like that is personal to you.

But I’ve had to take that over with (husband) now. And toilet him in the night. I get up sometimes three or four times in the night to toilet him, so everything personal; hygiene, everything else in the house I’ve taken on now. Um, I can cope; it doesn’t bother me I just get on and do it but, I suppose in a way, it’s brought us closer together, you know, because I just do everything for him. I sort him out in the shower; I just do everything.

Um, sometimes I’m shattered a lot of time, I’m tired. I do get very tired. Um, but you just carry on doing it, um, it’s what I signed up for, in sickness and in health and I just do it. Err, and it doesn’t change the way I feel about (husband), I still love him. Different love, when you get married obviously, but you still, he’s still the, to me, the person that I married as such. And thank God he’s got all his faculties that’s all I can say (giggle).

He hasn’t got the first sign of Dementia, because everything else I can cope with, but he knows I could not cope with Dementia. I went through a Dementia, or Alzheimer’s with my father, and Dementia with my mother and I know that if it ever came to that, I’d, I’d I don’t think I could cope with him, because I mean, I go, I do aerobics on a Monday night and I go to the gym on a Wednesday.

And I see a lot of friends, um, and he’s very good (husband), he keeps at me, ‘you must keep in touch with your friends; you must go out with them, don’t worry about me’. I do worry about him, obviously, because I’m leaving him, um, but we, sort of try and have a, a, I try and get him organised. So that if I’m going to be a long time, I make sure that. He might be upstairs; he’ll stay upstairs cos we’ve got another lounge upstairs. So, he’ll go up there, and then he can get into the bathroom. And our bathroom is for disabled person, so he’s alright in the bathroom. So, you know, as, but I try and organise it so that I have toileted him, so that he’s not worrying about that.

Um, so, and make sure he’s got things to hold onto. He prefers holding onto me, rather than his walkers cos I can hold, I can actually, lift (husband) off the floor which I’ve done many times. Um, and I can take his weight as well. And he feels more secure with me moving him, than he does pushing the walker. He pushes the walker and falls over then, he’s stuck. Whereas with me, I can hold onto him tightly and he’s quite safe; he won’t go anywhere. So, but I have it all organised.

**Interviewer:**

**There’s a bit of thought**

**Answer:**

Yes. You can’t just get up and walk out the door. And it’s like with Covid, obviously before, you know, you go outside the door, up, but I still do it, you know. Have I got my mask? Have I got my hand sanitiser? Have I got my wipes with me? You can’t just now pick up and go. You have to think about everything before you get out the door. Um, so, it’s experience. I’m not impressed with our GP Surgery whatsoever, um

**Interviewer:**

**Tell me a bit more about what you’ve experienced with them**

**Answer:**

Well, lack of. I think there’s a lack of empathy. Err, the last (GP) I saw, um, I thought, well he was, arrogant, rude and no compassion at all. I don’t expect people to be all over him, like a rash, I don’t expect that. but, we were just saying, I can’t, you know what, it’s so long ago since we went cos (husband) refuses to go. It’s a good job both of us are so quite well within ourselves, because (husband) won’t go.

But we were down there; we were late; he was late for seeing us, so we were waiting 20 minutes before we got in to see him and I honestly can’t remember what it was for. And I just happened to mention to him (husband) had had a low mood, and he turned, and he said to me. ‘well (husband) will have to find something that gives him pleasure and get on and do it’. And I looked at him and I thought to myself, ‘you haven’t looked at (husband)’. Because (husband) sits there with his eyes shut. (husband) can sit there sometimes for 3 hours with his eyes shut. And I thought you haven’t read his notes; and then, he said to me, ‘and you’ve had your ten minutes, you’re going to have to go’, And I was absolutely gobsmacked. And (husband) looked at me, and I know if (husband) looks at me in a way, cos (husband) knew what was coming cos the red was coming up. And (husband) knew what was going to happen and (husband) looked at me as if to say, ’don’t say anything; just get out’.

Um, and I have had a run in with one of the other Doctors down there, because they changed (husband’s) make of medication. Not the actual medication but the make of medication, and they didn’t read up on his notes to know that he’d taken a generic medication before, and it had gone straight through his system. So therefore, he wasn’t getting any Ropinirole at all. And when I came home (husband) was on his Repeat Prescription, and he was in such a state. The tremor was just off the wall and his DBS was working. And he couldn’t even talk to me; he couldn’t tell me; he was so upset. Well of course I started, he was trying to send an e-mail to the Doctors Surgery, and I started to read it. I just picked up the phone and phoned them and said could, I needed to speak to a Doctor. I was that I was livid. And luckily one of them phoned me straight back, and I let them have it. And err, he said to me, ‘well they’re all the same medication’. I said, ‘no they’re not’. Cos I said we research medication, (husband) researches everything. We research everything. And he said to me, ‘well, he’s been on this different medication for years’. I said, ‘no he hasn’t’. I said, ‘definitely now, because I keep all my repeat prescriptions’. I’ve got a box full of them cos I check. Before I get out of Boots, I check that it’s Requip. He can’t take anything else, and so I double check. And so, I knew that I mean I’ve got boxes of them upstairs. Loads of them. So, I knew when we’d been on the generic medication and he’d been really ill on it. Um, the side effects were dreadful, so I knew that he hadn’t been on it when he said he was on it. Anyway, I told (PD specialist), and she couldn’t understand it. She said, ‘I just don’t understand it’. And she went onto his records and she said to me, ‘but I can’t understand how they’ve changed it’. Now we could have taken it further; we possibly should have done because as I say I got all the repeat prescriptions, so I knew he hadn’t, but we didn’t.

But we didn’t, because we thought, ‘well, you know, we can’t get another Doctors’. You can’t just change Doctors cos nobody can take us cos there’s no Doctors, you know, around. So, we haven’t been back to the Doctors, but it’s just the lack (A) Communication and (B) the fact is that it was cheaper for them. Apparently we then discovered that they’d had an audit, down at our GP Surgery, and been told that they had to cut back on the medication side. So, they were changing everybody’s to a cheaper version, which is alright, if it doesn’t affect you.

But with Parkinson’s it affects the, the change is incredible. It’s not just a little bit, it can be massive which it was the first-time round. And I thought to myself, ‘for somebody who’s got now advanced Parkinson’s, and had this Parkinson’s for 17 years I would have thought they would have thought to themselves, ‘well, you know, we won’t touch that medication, we’ll say that’s what suits him’. And in fact, now on his Repeat Prescription it has got ‘do not change medication’. So, cos I checked that as well. Well, I thought, um, it annoyed me to the extent that (husband) never makes a fuss; he doesn’t make a fuss about anything.

We’re never down the Doctors Surgery at all. And I thought, you know, it, the lack of sympa, not sympathy but the lack of respect of p’haps ringing up (husband) and saying, ‘look (husband), we’ve got an issue; we’ve been asked to make medication cheaper; um, and (husband) could have said, ‘well I’ve been on it before, and the side effects were horrendous’. Um, and funny enough, (PD specialist), err, on his prescription wrote that it had to be Requip. So, it was on there from her, and they just ignored what she’d written.

So, that, I find that very, now, I mean, I think we got better service with the GP twenty odd years ago than we ever did now. Because (A) you can’t get through to them,, they just cut you off and (B) it’s such a rigmarole to get anywhere with anything down there. We don’t even b other, we just do not bother. If we’ve got an issue we either see, (PD nurse specialist) or we wait until we used to see (PD specialist). But of course, now we’re seeing, err, a (new PD specialist) now which we don’t know, we’ve not met her yet until October. So, you know, I find that very, it’s frustrating. And when somebody’s got something like that, you sort of feel that you’d get a big more empathy I suppose I don’t know, you know.

**Interviewer:**

**So, you don’t see your GP**

**Answer:**

I wouldn’t go do there if I was dying I wouldn’t go down there. I really, really would not go down there. I mean the last time I was ill, which was Easter of the Covid last year, um, I phoned 111 and I was in hospital within half-an-hour because they thought I was having a heart attack. And they sorted it out for me because it wasn’t a heart attack, I had a severe chest infection. But the pain, I woke up in agony, um, not knowing what it was. And phoned 111 and they, well I don’t, Ambulance here within 20 minutes and I was in (City hospital name). And they said to me that they were touting for business. They said, ‘oh good we’ve got somebody to come and see’. And honestly the treatment there was incredible, but I wouldn’t bother to go down there.

Really and truthfully if I’d have realised what it was I should have gone down to the GP, but I got far better treatment from the Hospital than I ever would have got down there. Well, for a start off, I wouldn’t have seen anybody. Um, but there they were absolutely brilliant at the (city hospital). So, no I won’t go to our Doctors if I can help it for any stretch of the imagination. Luckily for me, I’m in good health. I know I had that blip a week ago, but that was only a funny, I don’t know, some sickness bug going round. I only had it for 24 hours, but other than that. I keep eating fruit, piles of it I have for breakfast. And I keep as healthy as I possibly can.

**Interviewer:**

**Yeah, absolutely. And in terms of, I suppose over the years, you know, learning about Parkinson’s. How did you find that, getting information;?**

**Answer:**

Well information, (husband) does all the researching. I’m one, well I suppose stick my head in the sand for a certain amount of time because, Parkinson’s affects everybody differently so it’s not good looking at other people thinking, ‘oh my God’, you know, (husbands) going to get like that. Sadly, some of the people we saw, with Parkinson’s, cos, um, (husband) used to belong to (local area) Parkinson’s Group, and we used to meet them socially at, plus every month there was a Parkinson’s meeting. And err, um, I used to look at them and think, ‘oh my God’. And I used to think, ‘no, (husband’s) not going to get like that’. But of course, sadly, (husband) has got like that but, the main thing is he hasn’t got the Dementia. And nearly everybody I know, that’s on Madopar or Sinemet, have ended up with Dementia. And I know people say, ‘oh well, it’s not to say that (husband) would get Dementia if he went onto Madopar or Sinemet’, but nobody is prepared to put it in blood to say he wouldn’t get it.

And I think to myself, he’s got Parkinson’s, how unlucky is that all I need is for him to try. I mean to get the operation he had to go on Sinemet, well he couldn’t take Sinemet. (PD specialist) took him off that as he had a terrible reaction to it. Madopar we put, she did put him on Madopar, and he was on it for about 4 weeks, and then he got really depressed and he started to tell me he didn’t want to go on, and I thought that’s not (husband). So, I phoned her and told her Secretary, who was lovely, and she, then (PD specialist) phoned us straight back and said to me, he’s not to take it anymore. But to get the operation, we went up to the (hospital for DBS), they put him on a massive dose of it just to see if it suppressed the tremor which luckily it did so. Um, so that’s how he got the operation. But err, yes

**Interviewer:**

**(husband) does the research. Do you read the, read the?**

**Answer:**

No, I don’t cos I think to myself, ‘I don’t want to read something that I’. I mean, I’ve got to put up with it and look after him and I don’t read the research at all. I wait for (husband) to tell me (A) because, I’m, I’m just one of those people that I don’t want to know. You will (husband), you will tell me what’s going on. And then, you know, but, no, I, and to be honest with you I haven’t got time. I mean (husband) will spend ages on the, he goes on the American websites for drugs because it’s, they’re really good. But they have to be cos they sue for everything so; he does all the research on medication, but I don’t. I haven’t got, no, the time or the inclination really. I’m just one of these people, I think to myself, ‘well he’s got Parkinson’s’. He tells me what, you know, what’s affecting him and then because he’s so thoroughly researched it, then I know that what he’s told me it fine, that’s what it is, yeah.

**Interviewer:**

**And in terms of the DBS, you know, how was that experience from your point of view and**

**Answer:**

Whoosh.

**Interviewer:**

**Being referred and**

**Answer:**

Being referred to the (hospital). I mean (PD specialist) was brilliant, absolutely brilliant to get us up there. Um, I think (Neurosurgeon), who did the operation, man of few words, very few words. Um,

**Interviewer:**

**Is that the Neurosurgeon?**

**Answer:**

Yeah, yeah. He’s top, I mean he’s top in his field. Um, so, I wasn’t expecting. I mean our first meeting with him lasted, I think, quarter of an hour if that. and all he said was, ‘you should have had the operation 2 years ago, I can fix it’. And then, the Nurse that was with him said to him, ‘but (husband) hasn’t taken, he’s not been on Madopar or Sinemet. And his attitude was well I ‘m not bothered about that. But of course, to get the operation funded, (husband) had to try it; so, we had a real rigmarole before he was accepted.

Um, and I, it’s worked. It worked to a certain extent, but sadly, it hasn’t worked to the extent that I hoped it was going to work. Um, it’s like everything else, you know, you don’t really. Well in fact there was, we weren’t told anything about side effects at all, so we didn’t, I didn’t realise that it could have affected his eyes or his speech. Again, it can be different things to everybody else. Now I’ve discovered it’s quite common, um, and when we went up, err, 2 years ago, (Neurosurgeon) actually came and saw (husband). And he apologised. And he said to me, ‘I’m sorry it’s not worked a hundred percent’. But he said, ‘I can do it again’.

He said, ‘I’ll do the operation again’, he said. ‘But I need to switch (husband) off completely,’ and (husband) was having convulsions, so he said to me,’ I’m sorry’, he said, ‘but the risk, you’ve got to be turned off from um, the risk of a stroke is so great that he said I can’t operate again’. So that was a big blow because I don’t know whether. I think (husband) would have gone through with it again, um, so they switched him off and started re-programming the device to try and get over this. Um, but it’s never, err, it’s never been a hundred percent. His eyes still, it’s running very low because it affects him so, it does affect him so badly. Um, he has, if it’s up too high, his eyes tingle and that, that affects. He can’t see properly. So, it got to be run low, and of course the longer he’s had Parkinson’s, the tremor’s come back, especially if he’s stressed. Um, so, and his speech it pulls his mouth back, so I laugh at him and tell him he looks like a ventriloquist’s dummy.

Um, so, it, um, but on the other hand, if he hadn’t have had it, the tremor would have been so bad in his right hand, right side. Cos then it was appearing in the left. Funnily enough the left side, because he had the operation, he’d only just started to get the tremor in the left side. The left side’s been really good. And I, (Neurosurgeon) was right. If (husband) had had the operation on the right side, all those years beforehand, probably it would have been better because he wouldn’t have h ad to gone so deep to try and fix it I suppose, you know. But, um, that’s how it is.

So, but the actual (hospital), up until last year, had been brilliant, absolutely brilliant and they were brilliant. I mean, every month, when we went into lockdown they were phoning every month to see how he was. Um, we got to, um, August of last year and um, the Neuro Nurse that phones said that she would like to get (husband) up to have it all checked out and then we’ve heard absolutely nothing from them since. No phone call; no letters; no nothing. (PD nurse specialist) said really we ought to be chasing. Half of me says, ‘yes’, the other half says, ‘do I want to go up to (another city) to the (hospital) when this is all going on?’ so, it’s a catch-22.

I’m not sure I want to go up there, um, with Covid, you know. And, and (husband) is so vulnerable now that if he caught it, alright we’re all double jabbed, but if he caught, catch it, and it was bad he it cos he’s got flaming great disc stuck in his chest. So, you know, you sort of think to yourself, ‘should I chase or shouldn’t I?’ So, at the moment we’re in that, sort of, we’re not sure what we’re gonna do.

**Interviewer:**

**Covid has had some sort of impact.**

**Answer:**

Covid has had a massive impact. Um, up until then he was going to the gym twice a week; his mobility was, wasn’t brilliant but, he could walk. Covid came along; the gym stopped; everything stopped, obviously for all of us. I was alright because, women can always find something to do. You know, I cleared out wardrobes; you name it I did it. The house was immaculate. Um, but (husband) didn’t do the walking, you know, like we should have gone round the block every single day walking and got out. And we didn’t because, they were saying, ‘oh you know, be careful’. Cos every, nobody knew. Nobody knew did they? And so, his mobility got worse and worse and worse, and now of course, we’re now getting to the stage where we’re gonna have to have a wheelchair, which is on order. Which never thought we’d come down to. It’s like everything else. Probably if Covid hadn’t come along, he would have gone down slightly, but not as much as he has now. He really has gone downhill now. Um,

**Interviewer:**

**And has Covid had any impact on your appointments or**

**Answer:**

Well yes because we. Well, the first things, the first, I think the first-time round we should have seen (PD specialist) and we did a phone conversation, which is actually useless for (husband) cos he can’t talk on the phone. So basically, it’s a 3-way conversation. He’s trying to tell me what to say; he speaks so softly that nobody could hear him anyway. And so, I’m trying conveying what he wants to be said. Um, so, and then the second, then in October when we saw her, we actually saw her face-to-face. And ever since then we’ve done face-to-face with her.

I’ve got a telephone conversation with the new (PD specialist) but I’m hoping that we’ll actually get up there. Otherwise, it’s going to be a 3-way conversation. He gets frustrated; I get frustrated, and the poor Doctor doesn’t know what’s going on so, I’m hoping I’m going to get a phone call beforehand to say, ‘would we like a face-to-face appointment?’ And it would be much, much better than (husband) struggling to try and talk on the phone, well he just doesn’t talk on the phone and that’s all there is to it. So, yeah, Covid has had a big, um.

We, the Parkinson’s Nurse we’ve seen. The first time she did a telephone conversation, and she said that was a load of rubbish, so we’ll see face-to-face, and we’ve seen (PD nurse specialist) face-to-face ever since.

So, yeah, we’ve had um, face, we’ve had err, phone conversations with (speech therapist) about his swallowing, cos

**Interviewer:**

**Is that the Speech Therapist?**

**Answer:**

The Speech Therapist but then, they call it the Swallow Clinic. Um, about, his swallowing and that was two Saturdays they phoned to try and help with that. but again, you know, really and truthfully to see how he’s swallowing you need to see somebody. To put your hand there, to find out what actually is going on so that wasn’t very, that wasn’t very. I mean she had some good ideas, which we’ve taken onboard, err, which actually has worked.

But he’s had some funny symptoms, which again we’ve not done anything about cos obviously Doctors, and that’s been the most horrendous phlegmy cough. And that started last year. Every time we went to see somebody it disappeared, so we didn’t bring it up, and then it comes back.

So, and also, terrible Rhinitis, awful Rhinitis, which I asked the girls in Boots. I know the Pharmacist in Boots, and they looked up and said, ‘yeah, it’s common for people with Parkinson’s’, and they um, recommended a spray which instead of getting it on prescription I just bought. Um, and that actually has worked; it has helped.

Um, so, but we’re leaving it off at the moment. I don’t know whether it was Hay Fever that he’s had, um, whether it’s just started up as Hay Fever, or it, I suspect it’s all to do with Parkinson’s. I think the more it’s gone on, of course, with advanced Parkinson’s all these things affect, it all affects everything, you know. Mucus, and swallowing, it’s all the muscles, so I suspect it is all Parkinson’s, so we just, we try, trial and error at finding out things. So, yeah, we do.

**Interviewer:**

**So, I say, you’ve talked a bit, you said, different symptoms (yeah). didn’t want to go to your GP (no). You didn’t see your Parkinson’s, you used the Pharmacist**

**Answer:**

Yeah, yeah, we ask the Pharmacist. I try and speak to (pharmacist) there who’s very good. Um, cos I know her. So, and she’s been really good. And she came, well as I said, we researched it first of all before we, I went down there and then she looked it all up and said, ‘yes, it is all part of Parkinson’s’. so, she said, ‘try this and if it doesn’t work’, she said, ‘sadly you’re going to have to try and get in touch’. This is it; you’re going to have to try and get in touch with the GP, and I just went, ‘oh’. And she said, ‘I know, good luck with that’. So, everybody knows what it’s like, but anyway, so far we’ve managed to sort it out.

**Interviewer:**

**And have you ever needed to, I suppose contact (PD nurse specialist) or, you know, (PD specialist) to ask questions or?**

**Answer:**

No, I try not to. We, we try and sort things out ourselves because, um, I mean (PD specialist) has always said, you know, ‘if you want me, you can’. And her secretary is brilliant. She really is lovely. Um, so if I’ve had a problem, and for the life of me I can’t remember why the last time I had to phone her, which is a long time ago, but she’s always come back to me straight away. Um, but err, we always try and find, we find things out for ourselves, or (husband) does. He gets on the internet and Googles things and, trace, takes it further and, you know, sort of tries to help himself rather than rely on them. Cos everybody, you know, it’s all different to other people that symptoms they might have different, but (husband’s) always been the one to try and find out things for himself, so yeah. Um, my son, err, has err, um, he can get in touch with people in London through his jobs so, err, if it’s really stuck I, you know (son) done some research up there and spoken to people in London. So, yeah, he has dealing with the NHS in London so, um, I leave, I sometimes ring (son) and say to him, ‘(son) can you try and find out’, and he’s really good doing that. so, between everybody, we sort of try and not to, annoy anybody else, if you see what I mean. We’d rather try and sort it out ourselves – there’s no cure. So, sadly, so, err, you know, you have to try and help yourself really.

**Interviewer:**

**And how do you think, you know. You talked a bit about helping him, and how do you .. change over the last few years. Do you think it’s progressed since he’s had Parkinson’, your caring responsibilities?**

**Answer:**

Oh, they’ve got more. A lot more. A lot more. I mean, I didn’t have to do all the things I have to now, then. So, in the last, I would have said, showering; toileting, err, I’ve taken over helping in that, what I would have said the last 4 years. Um, and now like I, I have to feed him now so which I didn’t have to do before. He, he can start off, but I see he’s getting tired. Because he can only use his left hand, and he’s not very good with using his left hand, he really truly is right-handed, but he can’t use his right hand for anything. So, yeah, over the last 4 years I’ve noticed things have deteriorated, and I’ve taken overloads and loads of things now. Um, so yeah, it has made a big difference to me, looking after him.

**Interviewer:**

**And in terms of, I s’pose, managing his health. So, medications, appointments, you know. We talked about exercise and diet, you know, or anything else. What aspect do you find most challenging?**

**Answer:**

Um, that’s a. that’s a funny, well not a funny question. I suppose the most challenging

**Interviewer:**

**Difficult or challenging**

**Answer:**

Um, I think it’s the. First thing in the morning, getting him out of bed and last thing at night, getting him into the shower; sorting him out. Because he’s getting a little bit stressed and he’s tired at night, and in the morning his eyes are playing up. Um, agh, what else? I suppose because I do it, I don’t find it a problem. Does that make sense? I do it, I don’t think about it. I mean, I can’t (giggle) tell you what probably does, you’ll laugh at this.

I’m a fanatic, my bathrooms are immaculate, absolutely immaculate, you can eat off the floor in my bathrooms I’m paranoid about, I always have been. They have to be I’m, absolutely spotless. And I can guarantee that I’ve cleaned the bathroom; the floors are all washed lovely, and (husband) will want to go up there and use the toilet. I say to him, ‘I’ve just cleaned it’, and I know I shouldn’t, but I know what’s going to happen. And I go up there, and he goes to the toilet properly; I sort him all out; I bring him back downstairs and I’m straight back upstairs cleaning the toilet again (giggle). And that happens every time, every day, and sometimes it’s twice a day (giggle). And I think, ‘why did I bother?’ And, but I go up there and I scrub it all again, and it’s immaculate again. So, really I’m make a rod for my own back because I’m for ever cleaning toilets. But I, it’s just one of those, I always have been, I always have been. And, yeah, it’s quite, and I always think, ‘for God’s sake (husband), why can’t you go to the loo before I’ve cleaned it’. (giggle) But that, I suppose that’s frustration that’s coming out, yeah, that’s frustration, bless him. But err, yeah, I, it happens every day as well. I said to him, ‘I ought to put money on this, I’d make a fortune’, but um, yeah, that, that, that I mean, you know, you live with it and I think, ‘oh God, back upstairs again’.

**Interviewer:**

**But do you help him with his medications and prescriptions?**

**Answer:**

Agh, no. prescriptions, he does himself online, and I obviously collect them from Boots, so he does that. in the morning I know exactly what medication he wants. He’s not actually on a lot of medication, he’s only on 2 tablets and they’re slow release, because he makes the decision about what tablets (husband) takes, I have no input at all. Because he knows what he can take. He’s got a very low threshold of taking medication, the side effects, and he knows. If we up it, I mean he’s only on, 12 milligrams of Ropinirole, and when you think he’s had Parkinson’s for 17 years, actually 12 milligrams is not touching it at all I shouldn’t think. If he ups it by 2 milligrams, within 3 weeks he’s stressed. And he starts to get twitchy and irritable, and I don’t deal with that. And I just have to look at him and he says, ‘I’m gonna reduce it’. (PD specialist) was really good at this, she used to say to (husband), ‘I’m going to leave you to decide, up or down your medication’, she said, because she said. She was so good at knowing, what, how (husband) felt about medication. He doesn’t like tablets anyway. We’ve tried loads of different combinations and adding this that and the other to it; patches; we’ve tried Parkinson’s medication and that, and he can’t mix tablets. He can’t, he just can’t mix them, so we end up back on the, well we don’t ever stop Ropinirole, but it always comes back down to 12 milligrams. Um, and so really medication wise, I just get them out the packet in the morning; leave them where his Nurse knows they are, and she, you know, she doles them out to him. And he’s fine, I don’t have any problems with med, with that at all.

**Interviewer:**

**You take the medications out for him**

**Answer:**

Yeah, I just take them out of the pack. Cos I mean he wouldn’t be able to take them, cos of course they’re blister packs. They’re really difficult obviously, childproof, so I take them out the pack for him and put them by his drink, um, with his breakfast. I mean everything’s laid out for him, and she just brings him downstairs and feeds him. Um, he has his fruit and then she feed him his breakfast and makes sure he’s taken his medication. We take it dead on 9 o’clock every morning. Um, cos Parkinson’s medication you have to take as a specific time, you can’t just take it when you feel like it. But we’re lucky that he only has slow release, that we don’t have to take it every 3 hours or God knows what some people do take hundreds of tablets, but we don’t have to it’s only the two that he needs, yes that’s good.

**Interviewer:**

**And do you monitor his Parkinson’s?**

**Answer:**

Not really, no he just carries on (giggle). I don’t monitor it at all, except, I mean if he’s shaking I’ll, if he’s shaking badly I can put my hand on him, and it will stop. I tell him it’s; you know, his Parkinson’s knows who’s running the house and who’s leading this house. And I just touch him, and it stops. Or I’ll say to him, ‘(husband) move your hands’, and he’ll move them, and the tremor stops. So, yeah, but

**Interviewer:**

**I suppose with the DBS really, talked about all the stimulations and know a lot more about that. How, how did you, I s’pose, did you learn about it as it came along. Did you read up about it?**

**Answer:**

Err, no, I don’t read up on anything if I can help it. Um, no, I said to (husband), ‘right when’, if it’s really bad, his tremor, I can switch it off. And I’ll just say to him, ‘I’m gonna switch it off’. I switch it off and he goes mad, it causes tremor, and then I’ll put it back on again and often that will reset it. And it, and it’s, it’s alright. I haven’t had to do that for ages actually, but I do that sometimes for him, but I set it up for him. I put the harness on him and slot it all in, and try and make sure it’s, the device on the outside is touching the magnet on the inside, so that it talks to it and starts to charge it. So, I do that for him.

**Interviewer:**

**Every morning?**

**Answer:**

No, he doesn’t need. Only needs doing that now, we do it Sunday and Wednesday. Um, and because it’s running quite low, it’s not taking the power so err, I just do that for him. Um, but yeah, and that’s fine. I put on the harness, um, over him, and he just sits there for an hour and a half with this thing chuntering to itself, and then it’s done for 3 or 4 days, so it’s quite good. Um, yeah, it works well. And that’s not really a hassle, you know, he just sits there quietly, err, Sunday morning and err, then Wednesdays, so yeah that’s fine, yeah, yeah.

**Interviewer:**

**And um, you talked about access to Parkinson’s specialist, what other things like Physios, Occupational Therapist, Speech therapists ..**

**Answer:**

Well, wait, we’ve had. (husband’s) had Speech Therapy but, because the, um, Parkinson’s is affecting his muscles in his throat now, and speech, they, (PD specialist) said to be careful that he didn’t strain his voice. So, the Speech Therapist, accepted that, and she tried, and (husband) does try, but he can’t project his voice anymore. He can’t, he cannot, and if he does it it hurts. So, you just, I mean, I know he just said, I heard him say, well, I assume it was (name) cos he’s a monkey, err, err, err. I just have to know. It’s like when you’ve got teenage kids they all talk like that when you’ve got teenage kids (giggle) err, err. And they have a conversation like that, so I’m quite used to that. Um, so, yeah, err, so we’ve had Speech Therapy. He had 2 lots of that; then we’ve had the Speech Therapist, but she was to do with swallowing. (PD nurse specialist) is putting him forward for more physio, um, because he’s so, when he stands up he’s bend right over. And she, obviously, because he’s compressing all his organs, she’s worried about that, so she wants that to try and help. Whether it does or not, or I don’t know. And she’s trying to get him Botox, for his eyes, as well because if, because of the drooping, that’s of his eyelids, she wants him to have Botox to try and see if that will help. Um, but she wrote to the (DBS hospital) in October, asking them if they thought it might help and she’s had no reply from October. Cos we saw her a few weeks ago, and I asked (husband) to try and get in touch with them. The, the, whoever does it down here that (PD nurse specialist) knows, is willing to do it, but she doesn’t want to tread on people’s toes. I suspect that the (DBS hospital) are going to say they’ll pay for it, but I don’t think they will (giggle). But we’ll have to wait and see. Whether that helps or not because his eyelids just drop down and, and she said, you know, she’s taken photographs of it so, and the, I don’t know who she sent it to, can’t remember now, err, it’s either (city A) or (city B) said, you know, I t was bad with his eyes. And they would try, they were willing to have a go but. I said to (husband), if you don’t have it, I’ll have it (giggle) this Botox I’ll have it.

**Interviewer:**

**And how has it been going to (DBS hospital) and the appointments, and getting there?**

**Answer:**

Well, we used to, well, err. They always give us very early appointment. Normally what we do, is we go up the day before and stay in a hotel overnight. Well, of course, now with all this Covid, err, do I want to stay in a hotel overnight? And so, that’s another thing why we haven’t pushed it. It means basically that I’ll have to get up at 5, to get out at 6, if they give us a 9.30 appointment. Cos parking up at the (DBS hospital) is an absolute nightmare. Um, and Neurology has its own car park. So, to get there, and to get parked, you need to get there very early in the morning which I mean, it doesn’t matter I can do it; I’ve done it so many times. But we won’t be going up, staying in a hotel anymore I’d rather just go straight there. So, and they’re so kind up there. They really, they, everybody’s kind up there, you know, they’re really a lovely crowd of people we see up there. They’re really good. Um, and so, it’s not a hassle to go and see them, but err, it’s getting there when you got to be there at 9.30 or whatever.

**Interviewer:**

**You drive then**

**Answer:**

I drive, yeah, I do all the driving. Yeah, it’s a long drive but I don’t mind. I love driving, so I’ll drive anyway. So, I’ve always driven, so yeah, yeah

**Interviewer:**

**That’s; okay. And how have you found that, you know, (husband’s) care has been co-ordinated with (DBS hospital) and your physios. Has that been co-ordinated over the years?**

**Answer:**

Well really it’s completely separate. When (husband) had DBS, it was the (DBS hospital) that, err, got hold of, did everything with the Occupational Therapist. So, everything that we needed at the time, I mean they sent loads of stuff to help. A lot of it went back, err, because it wasn’t suitable for (husband), or maybe

**Interviewer:**

**Equipment?**

**Answer:**

It was equipment. Um, so a lot of it came from the (DBS hospital). Um, so really, I’m trying to think, oh (PD specialist) got us the bed rail. She sorted that out for her, us. Everything we needed we do through the Hospital, again I don’t go through the GP, I, as I say. So, and the Nurse is private, we don’t, I don’t have, I don’t go through the GP or anybody else, or Social Services for Nurses. I pay privately.

**Interviewer:**

**Was that by choice or?**

**Answer:**

Yes, yes. That was by choice. Um, the Nurse that we’ve got, wel there’s 3 of them, and the Nurses we have got are excellent. And they come at the same time, well they come between 7.30 and 8am every day but I know what time they’re coming. Um, and they’re excellent, absolutely excellent. And um, so, I’d rather have them. They’re actually all Nurse, they’re not Care Workers they’re all Nurses. So, and funnily enough, all, not one of them, but the other two have got relatives, close relatives that have got Parkinson’s so, you know, there’s no, that helps, yeah, so. But they’re all actual proper Nurses, so yeah, so

**Interviewer:**

**Have you looked into social care or is that?**

**Answer:**

No, I won’t even touch social care, unless it was absolutely desperate. I would not go through Social Services. I went through Social Services for my mother and my father, and well,

**Interviewer:**

**So, you’ve had experience with both**

**Answer:**

Very much so, experiences of err, of err, having Carers in the house especially with my mother. So, I wouldn’t go through Social Services and have Carers, err, Carers in the house, not at all, no.

**Interviewer:**

**And do you feel overstretched with what you do to help (husband)?**

**Answer:**

Sometimes, yeah. sometimes (husband) says to me, ‘(wife), you have not sat down’, ‘or you’ve had 4 drinks, you’ve taken a mouthful out of each one and they’re all round the house’, and he gets worried. Um, I, but I just keep going. I just don’t think about it, I just do it. Sometimes I think, oh, I love reading and sometimes I think, ‘oh I’d love to sit down for an hour and read’, but I think, ‘oh well you can’t’, so just, you know, I just get on with it. I mean we’ve got a gardener which is helpful and (husband’s) always said I can have a cleaner. Um if I ever wanted a cleaner, just sort it out, that’s not an issue. Um, but I don’t mind cleaning. I, I’d, and I said to (husband), ‘yeah, but it’d be no good because I’d want my bathrooms done every five minutes, it’d be no good would it?’ (giggle) ‘Can you come back in an hour please and do the bathroom again’. ‘come back after lunch and do the bathroom again’. So, no I, at the moment I can carry on. It’s a good, a suppose it’s just in me to do it, I just, you know, I’m not one of these people that needs to sit down. Sometimes I think, ‘oh God, I could fall asleep at the drop of a hat’. And you think, I just carry on, I just find I just do. I mean (husband) is good, he’s not, he’s not onerous to look after. Although as I say, some, I sit down sometimes and he says, ‘oh (wife), I could, I haven’t got my so and so’, and I think ‘(husband), I’ve just sat down’.

**Interviewer:**

**And um, you know, who supports you with anything?**

**Answer:**

Um, well my kids are brilliant. I’ve got a daught, a son and a daughter. Err, they both are, they both see Parkinson’s differently. (son) lives in London and his wife’s not well and I don’t expect, and I don’t expect them to be round here every five minutes. So (son), um, we zoom each other and text each other constantly. Err, (daughter), only lives ten minutes away, so if there is an issue I only have to phone her and she’s here. So, that’s not a problem, but her, her, she’s totally different. They’re totally different, obviously to each other, to how they view their father’s illness. I think (daughter), puts her head in the sand to the extent that she doesn’t want her dad to be as ill as he is obviously. (son), because he works within the NHS, err, but on the outside, um, of the NHS, he knows more about it. Um, so he’s more understanding. If he comes down he’ll take over. Nearly every year we have a family holiday, so I know that, when we go away, that (son) will do an awful lot. I mean (daughter) will but, (daughter) will be more helping me as such, whereas (son) will help his father. Um, so, you know, they’re very much, both of them are excellent, really good, but it’s how they view their father’s illness, you know. (son) knows it’s bad; (daughter) knows it’s bad, but it’s how you cope with these things. Nobody wants to see their parents ill, you know, you want them to go on for ever.

**Interviewer:**

**And what do you think the impact has been on your life and your social networks on a day-to-day basis, or has it had any impact?**

**Answer:**

Yes, it has to the extent of. You can’t just, as I said before, you can’t just get up and walk out, you plan. Um, social life, we used to do so much; we’ve got a bit circle of friends. So, up until Covid we still managing to go out for meals together, err, a big crowd of us. Um, but I don’t think we’ll be able to do that now. Once, you know, obviously it’s opened up now.

**Interviewer:**

**And do you think that’s cos of (husband’s) mobility?**

**Answer:**

Yes, (husband’s) mobility, definitely. Um, I mean, obviously when the wheelchair turns up, it’s how (husband) feels about going out somewhere with the wheelchair. Will he want to go to a Restaurant where everybody, well, that’s the next thing. It’s all very well saying, ‘we’ll all meet up and go to a Restaurant together, but have they got the facilities. I have to take him now, and to obviously toilet him, and have they got a disabled toilet that’s big enough for a wheelchair. It’s not, it’s not easy now, you’ve got to think of all these things, so it won’t be the same. Um, it won’t be the same at all once we all start going out. Um, and (husband) feels safer in his own home now. It’s getting to the stage where, we, I love my holidays and, it’s getting to the stage where you book things, and I booked holidays and I think to myself, ‘I think you’ve done a silly thing here because you haven’t thought this through’. So that’s, that’s, that’s a worry for me now that, we’ll, will we still be able to a. We go to a cottage down at, outside (city) which is lovely, which I can cope with (husband). It’s all open plan, so that’s that’s alright. Um, but I have booked a holiday, a National Trust holiday, next year that I think I’ve made the biggest boo boo out, but anyway we’ll have to wait and see. I might, I might palm it off onto one of my kids and say, ‘please go; take this holiday because I don’t think we’re going to be able to access it’. You know, it’s like everything else. When I booked it, (husband) was walking, and now he’s not, so you know, I’m

**Interviewer:**

**So, lots of things to think about, not just the**

**Answer:**

Exactly. And I just think, ‘oh it’ll be alright, it’ll be fine’. And then now I’m thinking about it and I’m thinking, ‘ut oh’, I don’t think it is. I think you’ve made a boo boo. Um, so, yeah, um, we’ve got a family holiday booked for next May, um, but that’ll be alright cos the whole family’s going so (son) and (daughter), and (daughter’s) husband and (son’s) wife will all pile in. You know, it’ll be alright. But err, yeah, but when you do things, you do, it’s like everything else isn’t it, you’ve done something and you think, ‘actually that’s the most stupidest thing, why didn’t I think this through’. There we go (giggle)

**Interviewer:**

**And um, yeah, have you had any financial expenses because of his Parkinson’s?**

**Answer:**

Um, err, well obviously his wheelchair, his walkers. Um, we’re both lucky that we’ve got very good pensions so, moneywise we’re, you know, we’re very lucky compared to a lot of people. We are very lucky. Um, so yes we, we have had extra expenses. I mean, like the bathroom, we had to, that was, we had to have a wall moved in the bathroom which obviously. I mean we didn’t pay VAT on it obviously, because it was being dismantled for a disabled bathroom, but the bath had to go out. And, well, we’d already got a shower up there but anyway we’ve got a bigger shower now. A walk-in shower and all aids for (husband). So, we had to have one of the, the fourth bedroom was made smaller to get, to make a really big bathroom for (husband). So, yes, we have had extra expenses that we wouldn’t have had before but,

**Interviewer:**

**So mainly for equipment and aids and things**

**Answer:**

Yeah. the bed rails, obviously they came from (city). They came from the National Health so that, and his perching stool. Um, but we had, the bathroom we paid for ourselves, you know, but I don’t think, well we wouldn’t have got any help with it anyway, so we just, you just get on and do it. So, um, yeah, so apart from that. I mean the wheelchair that we’re getting is, I don’t know, £1300 I think so, yeah. But it’s going to help (husband) get out the house, where so, you just go with it, but as I say we’re luck that we can afford it. A lot of other people can’t, so yeah

**Interviewer:**

**I suppose just thinking of your experiences of the healthcare system over the years, you know, what do you think can be improved to try and, you know, help you manage someone with Parkinson’s, if there was anything?**

**Answer:**

Um, when, in our situation, I think we’ve done it ourselves because (A) we can afford to, but I think if you couldn’t afford things, um, there needs to be more joined up. But I mean I’ve got a friend, sad news wife’s got Parkinson’s, and she’s now had to go into care. But it was him trying to deal with all the Agencies, you know, social care. It was like a revolving door. One minute one person turned up, yes they’ll sort this out and then he’d not hear anything. He’d try and get hold of them and they’d disappeared. And then he had to start again with somebody else, so it needs to be more joined up I think. The Agencies need to be joined up, but of course, it’s like everything else it’s a revolving door. You know, people come, and they’re there 5 minutes and they’ve disappeared. So, in our, because I’ve not dealt with them because I don’t need to. We’ve done everything ourselves, I, at the moment, I’ve not needed anybody, anything else to do with its cos we do it all ourselves. (husband) researches it; we look; we go. We don’t, we go to a proper place that deals with like wheelchairs and (husband’s) been measured for one and the wheelchair’s being made for him. So, it’s coming bespoke for him, you know. Other people can’t do that, but we’re luck that we can. So, I think if, for people that can’t afford it, it must be a nightmare. It really must be a nightmare. Um, we are ver, I think we are very lucky that, you know. Alright, we could have had lovely holidays, more holidays and travelled the world like we used to but, it is what it is. And now instead of doing that, we’re spending the money on things that make it, life easier for (husband), and that’s what it’s got to be.

**Interviewer:**

**Yeah, absolutely. And I suppose, thinking about yourself, you said you don’t have any medical conditions; you don’t take any medication**

**Answer:**

I do.

**Interviewer:**

**What’s that for?**

**Answer:**

Well, I got horrendous Hay Fever. I’ve had Hay Fever now for forty odd years, so I live on tablets for Hay Fever and it really is bad. Mild Asthma, um and then cholesterol. I’m on Cholesterol tablets, oh, and I’ve got an Hiatus Hernia so I don’t have anything that’s fat. Milk, cream, nothing like that, so I am, otherwise I have to take an Omeprazole for my stomach, but I try to not take that if I can. Well, so its diet really and I try and look after myself there.

**Interviewer:**

**And what else do you do to try and look after your health?**

**Answer:**

Aw, right. Well, I do loads of stuff. I mean walking, obviously. I do my Aerobics on a Monday night; I go to the gym on a Wednesday, and I do a real good workout. And I do free weights, I do free weights that’s how I can lift (husband), so I do a lot of free weights. And I’ve got weights in the house. There’s a bike in the garage, an exercise bike in the garage. Um, so there’s every opportunity here to do things, in Covid I did use them I must admit. (husband) uses the bike, um, so, and the weights I use upstairs, so yeah. so, um, and I normally go to Aquafit down at (local town) but, um, with Covid, although it started up again, I’m a bit, not sure, not sure about that.

**Interviewer:**

**And I suppose has helping (husband) affected how you look after your health or?**

**Answer:**

Yeah, I mean, I still, err, my health, I tend to, it goes on the back seat my health. Cos (husband) comes first. But I’m so, I’ve been so lucky that I’ve not been ill, um, ill, ill, ill, if you see what I mean. I’ve only ever had, you know, the chest infection which was, don’t ask me how I got that I’d been running the day before. So, how that came about, you know, there we go. Um, I never think about it; I just do not think about it. I’ve got very short temper with my health, anyway, as (husband) will tell you, Um, if a get a cold or anything like that, I’m absolutely a nightmare, I do nothing but moan, ‘how dare I something wrong with me’, so I never actually think about my health at all. I think it’s, it’s better that way cos I just don’t think about it. It’s just, I get up in the morning; I feel alright, that’s fine (giggle); carry on, carry on as normal.

**Interviewer:**

**Is there anything else you’d like to add about, you know, helping to look after (husband’s) health that we haven’t talked about. Any other things that you do other that what we’ve already talked about?**

**Answer:**

No, I think that’s it. You know, I just, as I say, bless him, he’s easy to look after as such. Um, and he doesn’t, sometimes I say to him, ‘you’re getting old person; you’re getting very imp’. You know, he wants, I’ve found, I have found that if he wants something done, it’s no good trying to, I just do it there and then. Because he’s a, he’s now got to be a worrier which I find, I laugh because my mother was a worrier. And I’d say to him, ‘you’re just like my mother’, now. It might snow in May (giggle). She always used to say, ‘I can’t come to see you in May because it might snow’. ‘Mother it’s never snowed in May’, ‘but it might’. And I say to him, ‘you’re just like my mother now, it might snow in May’. So, yeah, if he wants something doing, I just do it, because otherwise he worries. And so, you know, I just, it’s just one of those things. And again, it’s Parkinson’s, you just, you know, I just put up with it (giggle)

**Interviewer:**

**That’s great. Thank you very much for that, um, that’s very helpful.**