# Interview C02\_300621

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| * Length of diagnosis – 9 years * Recent caregiving role in the last 2 years as other siblings passed responsibility to her * Person with PD also living with 97 year old mom – additional caregiver strain * Caregiver stress |

**Interviewer:**

***If you wouldn’t mind I’d like to start by asking some questions about (name) health if that’s okay with Parkinson’s. You know, how, when was he diagnosed with Parkinson’s?***

**Answer:**

Um, I believe he was diagnosed in 2012, but he feels that he had it quite a number of years before that. so, he must have, um, felt symptoms coming on before that. I suppose, I, I’m sounding quite vague cos um, I, was out of the family situation from 2008. I was out of the family. I didn’t have anything to do with *(oh right*) him or my mother until, uh, about 2019 so there was that gap; quite a gap (yes, of course)

**Interviewer:**

***So, when did you?***

**Answer:**

But I heard all sorts, and I know my other siblings, um, told me what was going on, so I was aware of, of what was happening with him, yeah.

**Interviewer:**

***But from your point of view, from when you’ve been involved, how has it been, you know, tell me how that’s been since***

**Answer:**

Since I was involved. I’ve been involved now, um, since I would say, um, fully occupied with it let’s say, since last year. Prior to that, um, my other brother um, and his wife, had been um, down as his Carer and they were, over the years, a certain number of years as his, progress, the disease progressed. So, they were dealing with things like aids in the house; like things for the bed and walkers and that kind of thing, um, and any other things. They were predominantly dealing with it. And then um, um, last year, oh well just prior to the year before that, 2019, I had said that I would help out with setting in place Power of Attorney, so I came back into the family at that point. And, um, set up a Power of Attorney for both of them, mother and *(name)* because their situation was such that it really did require that, and it was rapidly requiring it. So, I organised all of that. And that was happening last year, that all finalised in March and then of course the virus started. And um, everything just seemed to get worse because *(name)* um, and also his medication changed which he couldn’t deal with. He couldn’t deal with the change and, err, his health and that, it was just, like chaos really. And my other brother, and his wife, really and truly didn’t want to be involved with him anymore. And slowly but surely, it fell to me; they put it onto me.

**Interviewer:**

***And just describe some of the things that you help (name) to do with his Parkinson’s; just tell, what do you help him with?***

**Answer:**

Um, err, the first thing I did was ah, major thing was, um, well combined really. Err, was thinking about setting in a Care Plan and having to deal with Doctors, that was the first thing, dealing with the Doctors and the medication. And, um, then, the Council; the Frailty Team; the Nurses that were dealing with him. Um, they all said that he needed the Care plan; through the Council how much money did they have. So, then I had to undertake all the financial stuff, so I had to deal with the Bank. Um, get put onto the Bank records that I was Power of Attorney and then I had cheque books and card, you know, to spend their money when I needed to, that kind of thing. And, um, getting a stairlift, we, I got a stairlift. Um, and, err, that was the start of it really.

**Interviewer:**

***And how was that experience, dealing with you know, Doctors, Nurses, Social Care, lots of different***

**Answer:**

They were all incredibly helpful, incredibly helpful at that point, um, because I was, up until that point, my sister-in-law had been dealing with it, or dealing with the Doctors. And my youngest sister, the youngest in the family, she had some dealings with it over the years. And they’d all been talking about, do they need a care, go into a Care Home, this that and the other thing, and I was unaware of any of that. But, um, err, over the weeks it, as I was taking it all on, all of those things began to fall into place and having to also set up, um, meals, meals coming in where he couldn’t, he was starting to not really. He’s never really wanted to do very much anyway, but, and he’s not domesticated but, they needed, and they, both of them weren’t eating very well.

And my mother, also, in about March, she suddenly became ill so, you know, I had all of that as well. And she was diagnosed, we actually thought she was going to die, because she had, she was diagnosed with Hyperparathyroidism. But, um, the medication balanced her out and she’s been okay, you know, she pulled up and um, she’s functioning alright. Um, obviously a 97-year-old woman is not going to become sprightly again so, um, err there’s that situation. But it was really very, very difficult setting up laundry; having to get the laundry, um; changing beds cos they hadn’t done any of that. I mean it was just an absolute nightmare. At the time my sister-in-law was helping out, but it was obvious that she didn’t really want to do anything.

**Interviewer:**

***And it, when it all started, I suppose did you have much information about where to go. What you needed to do?***

**Answer:**

No. not really, no. My other sister-in-law, my other brother I mean there’s loads of us. My other bro, I mean I’ve got another brother, younger brother, that lives in *(city name);* my sister-in-law there she’d been through all of this with her mother and she rang and gave me, she was the most helpful really. Loads and loads of hints, what to do with um, with how much money they needed to have, or they mustn’t go over such and such money, in order to get the Council help. And, um, also how to deal with the Bank; what to do with the Bank. She gave me lots of information as to what to do, that was incredibly helpful. And my youngest sister, she’d had some dealings with some of the Social Workers on the … so she had lots of different things, so I had all of that. But, um, it was still, it was enormous. Yes, it was absolutely enormous. When I look back, and read my diary because I just, I wrote everything down. I don’t know how I got through it.

**Interviewer:**

**Was it quite a lot to take on?**

**Answer:**

I don’t know how I got; I really don’t know how I did it.

**Interviewer:**

***I suppose it was useful knowing people who had access to, what about information from your Healthcare Professionals; Social Care, or you know, any professionals what, did you get any information from them?***

**Answer:**

From the Frailty Team; the Frailty Nurses. They explained it, again, that was really more or less to do with, um, they mustn’t go over £23,250 you know, so quick let’s spend some money. Get the stairlift fitted which, um, we did, but um, and then once the Council was involved, and the Social Worker was appointed to *(name),* um, she was very helpful as well. Very very helpful. Um, but it was very bity, really to start with, because all of a sudden he couldn’t manage his tablets. And he just went downhill very quickly, and we hadn’t got any medication taking regime in place.

And of course, and my mother as well, she had medication she had to take. And he couldn’t give it to her to medication, I mean he’s such an anxious person and he just couldn’t do it. And he just went downhill. And, and, he, err, one day he, my sister-in-law, and my brother, that had been looking after him over the years, they were, they’d set up the Carelines on. So, then they was on the end of the Careline, and they were getting calls at night and all sorts of the day and night where he was falling or, he was phoning them and so on.

And one day, he just, they went, he, they had a phone call in the morning, and he couldn’t get out of the chair. And my sister-in-law and her daughter, my niece, they phoned round Care Homes and they just, both of them, went into a Care Home, for Respite. We all agreed it was Respite, for a couple of weeks, but unfortunately it turned into 5 weeks. So, I had to deal with all of that cos really and truly my sister-in-law, or my brother, wanted them to stay there, But *(name)* and my mother, they thought they were going home, I mean it was very, very difficult family situation.

**Interviewer:**

***Yes, very stressful times it sounds it***

**Answer:**

Incredibly, incredibly. Yes, because I knew that *(name)*, they, they wanted to stay, go home, stay at home, but obviously they couldn’t go home either until *(name)* had a Care Plan. So, I had to juggle all that, and there was a couple of thousand pounds; two lots of £900 for both of them a week, you know, having to deal with that as well. And, err, the family situation where I got a sister-in-law desperate to get out of it, and um, trying to persuade them to stay there and oh, I can’t describe to you have she, she sort of promised, she said ‘well a couple of weeks and we’ll go and clean the house up and they can come back’. Of course, all that stopped.

**Interviewer:**

***Of course. And obviously with (name) was having difficulty with his medications (yes). Is that something you’ve helped him with, his medications?***

**Answer:**

Yeah. What I, what I did to start with, um, I just racked my brains and thought what could I do and asking the Frailty Team, and they were telling me about Blister Packs and so on. And I was looking online all the time for the different pill dispensers; bought the different pill dispensers; one for her; one for him. And he couldn’t get on with any of it, it was all, God, dear, it was all unbelievably difficult. And I devised a, a plan, where I got these little small plastic pots, and I set them all up for each day with all the tablets in each day, and, um, it kind of worked to start with but then it didn’t. Hers, I’ve got that set up for her now and that still works. But for him, it didn’t work, I mean, and then I stuck these tablets on a piece of paper, I devised it all. The Social Worker was quite impressed with it.

Um, but thankfully I found this carousel pill dispenser (*what does that do?).* it’s a carousel; it’s a round machine, dispenser, and um, it comes through uh, the Careline people where they have all these different aids they’ve got in the house. They pay a very, very tiny amount of rental for them and this was one of these things. You didn’t have to, it cost a couple of hundred pounds, but you didn’t have to pay for it, just through them, a very very good service. And, I’m in charge of that. So, I set it all up and it’s all the tablets that are in this dispenser, and there’s a weeks’ worth in there. And it’s all timed; and an alarm goes off; and when the alarm goes off he has to pick it up; turn it upside down; tablets come out; then he turns it back up and it beeps to tell him that’s okay; Puts it down and then it moves on. And the next dose is there ready. So, he got to grips with that alright, apart from then the little lid that keeps the tablets in got struck. (*alright, yes*) So, I had to take that off.

So then he could get to the tablets and that, then he, cos he can, it’s all open, he looks at them and he thinks he hasn’t taken that tablet; he forgets that he’s just taken them, so there’s that difficulty with it. But the thing did actually break down a few weeks ago, so we’ve got a new carousel with a lid back on it and its working well. he has got to grips with that.

**Interviewer:**

***Yes. But I suppose it’s a bit of trial and error and research from your end.***

**Answer:**

It was such a worry cos the tablets, the medication is such an important part of his whole scenario. Um, and he goes downhill quite quickly when the medication, um, goes awry.

**Interviewer:**

***So, you’ve noticed that? (yeah) the medication***

**Answer:**

Yes. A couple of times when that’s happened, um, he’s fallen. And last year he fell and for whatever reason, I don’t know, both of them my mother and him, um, failed to press the alarm. They got an alarm (*yeah, Careline)* on their wrist. And he was lying on the floor all through the night, for 8 hours. And then in the morning when my mother raised the alarm to a neighbour, and then the Paramedics came in, he was in hospital again. They rushed him off to hospital.

**Interviewer:**

***Was it because of the medications ..?***

**Answer:**

Yeah, yes. And lying on the floor for over 8 hours. So, he was in hospital, and again, they wouldn’t let him out until the Care Plan was all in place. When he goes into hospital, the Care Plan stops, that’s the trouble. And then they have to reinstate it and it all takes time, so he’s either in Hospital, or he’s, they sent him into a Respite this last time.

**Interviewer:**

***Um, okay. And how many medications does he take in a day, do you know?***

**Answer:**

He’s got 4 times – half past 9; 2 o’clock; half past 6 and 11. So, um, and the last one at night includes the Mirtazapine which is the anti-anxiety medication.

**Interviewer:**

***And other than his Parkinson’s does he have any other conditions?***

**Answer:**

Um, I think it’s probably his Parkinson’s that’s affecting the waterworks and the bowels, and he does have Haemorrhoids that have been playing up a bit and bleeding. He has had that. Um, apart from that not, other than mental problems. High, high anxiety always has been incredibly anxious person, very very anxious; OCD; quite obsessive about stuff; um, not successful in relationships and he’s, he’s got no confidence whatsoever. And my mothers’ always hung onto him, not let him go. And I’ve always tried to help him to get a life, you know. He came to live with me when I lived in *(town name)* for quite a number of years, and he did manage to get away then but went back home. So, it’s quite sad, it’s very sad.

**Interviewer:**

***And I suppose, in terms of his Parkinson’s you know, how much do you know about Parkinson’s; where did you get any information about Parkinson’s if you have?***

**Answer:**

Um, well, my dad had Parkinson’s. Um, I, he didn’t have, I mean, as I remember my dad. My dad used to fall asleep; he developed Parkinson’s quite late. And Parkinson’s didn’t kill him he had Lung Cancer, um, but he wasn’t a smoker. Um, he just fell asleep and he dribbled a bit, um, but he, you know, you didn’t sort of, and he was shaky but I never sort of saw him at any, and he was very frail, anxious man as well. Um, but we never sort of got any information about Parkinson’s when dad had it, not really. Um, they just dealt with it cos I was away from home then anyway, I was living in *(town name).*

**Interviewer:**

***What about now with?***

**Answer:**

But now, since I’ve been involved in the way that I have, I, um, got in touch with Parkinson’s UK and once again they are incredibly helpful, incredibly kind, caring. Um, err caring about me, um, they’ve all been like that. Everybody I’ve been involved with, they’ve been anxious about me, as well, because they’ve seen, you know, what I’ve had to take on, you know. Um, but Parkinson’s, and they sent me stuff as well. They sent me lots of different booklets and all sorts of things and given me advice. Um, and, um, I’m hoping that they’re going to have something starting up this year, you know, that can perhaps, some kind of Groups starting.

**Interviewer:**

***Obviously Covid has stopped some of that I think.***

**Answer:**

Yes. Oh, it’s made, it’s made the whole situation a lot worse.

**Interviewer:**

***And how did you know to get in touch with Parkinson’s UK. Was it something you looked up on your own or?***

**Answer:**

Yeah, yes

**Interviewer:**

***You found that was helpful. (yeah, yeah). How easy or difficult is it to understand the information that’s given to you?***

**Answer:**

Oh, yes, it’s very clearly all set out, yes, yes. Um, but *(name)* is, he was helped enormously by their local representative here, years ago when he was first diagnosed and um, then he needed help and a lady called *(Parkinson’s UK support worker),* and he’s never stopped talking about (*Parkinson’s UK support worker)*. She must have been an amazing person because she’s obviously went there, and she’s just, she just sorted everything out. And I’ve come across loads and loads of stuff that she’s, she dealt with all the financial stuff; she must have taken all his, um, DWP stuff, all his Pension Credit, um, what do you call it, um, AA, um, the Attendance Allowance. Um, she’s dealt with all of that and she’s got him all the money that he’s entitled to and um, he just speaks so highly of her, but of course now she’s retired.

**Interviewer:**

***So, was she a Parkinson’s Nurse Specialist?***

**Answer:**

No, she, no she wasn’t a Nurse. (*okay, no)* He’s got the two Nurses over here, there’s two, *(PD nurse 1)* and, someone *(PD nurse 2)* somebody, but, that he’s seen in the past. And, you know, he’s got to know them, and they’ve got to know him I think, but (*Parkinson’s UK support worker)* she was, she worked through Parkinson’s UK, she was part of them. And she sounds amazing that she really did do all she could for him.

**Interviewer:**

***And, I suppose, how have you found (name) health care appointments. I don’t know how many he has, or how often you go with him to his appointments?***

**Answer:**

Well since last year I have been going. I have been coming here, um, with him. Um, it’s only a few times I’ve been so far. Um, the first time when he was in *(care home)*, that 5 weeks in respite, that first time, I took him to the Doctor to get checked over when he came back.

**Interviewer:**

***Is that the Surgery?***

**Answer:**

The Surgery, yeah, *(GP name)*. He was, he was very good with him. Um, err, what other things? Um, bringing him here, yeah, I brought him here. Um, where else have I taken him? I think that’s it so far, um.

**Interviewer:**

***And how have you found coming to appointments or going to the Surgeries?***

**Answer:**

Okay, yeah. there’s, I mean as far as I’m concerned they, everybody’s treated me incredibly well because now he’s, he’s difficult to understand, very difficult to understand and even I can’t hear him sometimes. Um, the trouble with *(name)* is he, you, you don’t know, you can’t, sometimes you can’t tell whether he’s just not, he’s so frustrating he’s not trying enough.

Or he really is, you know, really is a struggle for him because all of a sudden he’ll start to speak quite clearly or you know, sometimes you cant work it out whether he’s playing you up, you know, like a naughty boy to get attention. Or whatever it is you just don’t know. And other times he’s absolutely dreadful you can see the mood is bad, not bad but unhappy and, you know, because he, he’s very frustrated with his life.

And he hates all the Carers coming in because it’s an intrusion into his home and his life. He keeps saying to me ‘can we stop this contract now; can we just do it; I’ve got enough money coming in haven’t I; how much money’. And we go through all of that again and I have to say, ‘you’ve got to have care, and so has mother she’s got to have care’.

**Interviewer:**

***That must be difficult trying to have that conversation, knowing what you think what is probably the best for him***

**Answer:**

Yes, yes, that’s right. Because the Carers there, you don’t just get one or two or three, you get quite a number of them, they’re all different ones. And you know, you think they’re going to come in at half past 9 in the morning or whatever time in the morning and they’re, you know, its 11 o’clock; 12 o’clock and that’s supposed to be the morning to come in an help them wash and dress, and you think, ‘no it doesn’t happen like that’. So, you have to take what it is, that’s what it is and it’s helpful.

**Interviewer:**

***Of course. And I suppose in terms of anything else you help; you help him with his health. It helps him with his Parkinson’s, can you think of anything else you do to help him with that?***

**Answer:**

Well I, I, and its always been the same with him, as far as I’m concerned, apart from that very long break we had, um, I’ve tried to chivvy him along and try, I’m always trying to praise him. I go through the psychological route of trying to, um, encourage and um, inspire or, set up things that he might interested in to do like, um.

I must admit I did the wrong thing sacking his gardeners, I shouldn’t have sacked his gardeners. They were two old fellas who came in, well one old fella and one other, and they really weren’t very nice. I mean this garden is horrendous, and I thought I’d get a nice lady gardener because he used to be obsessive about Roses and I thought let’s get him, and I sent away for some Roses. I thought that’s a good idea, maybe I could get him focussed on Roses. It hasn’t quite happened like that because, he’s such a negative person, so he’ll find something wrong with everything and its trying to talk him out that way of being but it’s very, very hard. (*of course, yes*) And at this stage of his life, and the Parkinson’s, I don’t suppose I’ll make that many inroads. Because I tried all my life to help him, you know.

**Interviewer:**

***It must be quite difficult for you.***

**Answer:**

It’s very difficult. It’s very difficult, yes it is.

**Interviewer:**

***And, I suppose, have you had other contact to other Healthcare Services, I know you talked about coming here or going to the Surgery, have you anything like Physiotherapists, Nurses or anybody that comes***

**Answer:**

Yes, I’ve, I’ve met, err, I don’t know about the District Nurses, I think it’s always the Frailty Team that come along and, um, err they certainly come for mother with the legs, cos she’s got puffy legs and so on, but they come, but they’re very, very good. The Physiotherapist, I’ve had phone contact with them because this last time when he, because I think I mentioned when we went for the appointment with *(PD specialist)*, he collapsed after he had the vaccine and he was in Hospital for 2 weeks and then he was put into the Care Home.

And the physio, I mean she should have gone in there straightaway, but they didn’t refer him quickly enough. So, it was only when he was going out the physio appeared. So, she contacted me, um, about, um, what she was hoping she would be able to do. Um, but I haven’t, I can’t think I’ve met any, oh the other service that he did have, um, was *(psychologist)*. She, um, she was a fantastic person and he got on very well with her. She worked through, she comes, she works with the Psychiatrist at *(psychiatric unit)* in *(local town)*. And um, err, must have been *(GP name)* his GP, must have referred him, um, to the Psychiatrist and then he set up *(psychologist)*. And *(psychologist)* used to go around there, go in the home, and do an hour with him looking at different aspects and what he could do and so on, and talking things through with him on a psychological level. And, um, I think he benefitted from it, but once again, the same with the physio, and he’s coming here. They’ve set him up, *(PD specialist)* was marvellous.

Where *(GP name)* didn’t get any physio this time, it’s straight here so; he’s been here this morning, (*okay)* got four, he’s had two sessions. But you see, same with the Psychology and the physio, he’s got his exercises to do at home; doesn’t happen, you know. He doesn’t ever, but, the Carers, he’s got some male Carers coming in, and he has really gelled very well a couple of them, certainly one of them. And they’re taking him out for a walk every day, which is very beneficial and I’m hoping that maybe they’ll do a few exercises as well. so, bringing that into, into it. Because .. the physios always send him home with a folder, and all the exercises are all drawn out very clearly, and they’re lovely simple exercises but good, you know. And they also send him away with a booklet from Age Concern about how important movement is with Parkinson’s disease.

**Interviewer:**

***And do you think that’s helpful having all these books?***

**Answer:**

Well I said to him, I said to him a couple of times, ‘*(name)* you must read this it’s really really helpful’. I said ‘not just on the physio and movements on it, there’s other things’, but I don’t how much he does once I go out the door. Um, I don’t think he does a lot of reading. He used to do a lot of reading, but I don’t think he does very much at all now.

**Interviewer:**

***And how do you think your, (name) care has been co-ordinated between all these services and you know, obviously there’s been quite a lot that you’ve helped him with as well, how have you found the care being co-ordinated?***

**Answer:**

Um, co-ordinated. Um,

**Interviewer:**

***You can say it’s not been co-ordinated, that’s fine, how do you feel about?***

**Answer:**

Um, I think I wouldn’t like to work in the care industry, I think it must be incredibly difficult to actually organise rotas and all of that because, *(name)* and my mother aren’t the only people that they’ve got to care for they’ve got so many people. But, um, like I said before, you, there’s not really a basic routine. You’d like to think there would be, because you sit down with the, um, with the Social Worker from *(local)* Council and you agree a Care Plan.

Right *(name)* needs help with so and so, so and so, so and so, which can be dressing; washing; shower; food, but I mean some of that he does himself. He doesn’t want to let go of doing that, but sometimes they do it for him. And they’ll come in at such a time. Well to start with we had people coming in at 7 o’clock on a Sunday; then 8 o’clock; then 12 o’clock and all sorts, I mean he couldn’t. 7 o’clock in the morning he said, ‘I’m retired I don’t want somebody going in’, and of course they’ve got a, a key safe so they’re coming in the front door. There’s a loud shout ‘here I am’ and he hates it, he absolutely hates it. It’s an intrusion into his life.

And then my youngest sister, she’s my, very concerned with my mother having attention. She thinks *(name)* is getting all the attention so, she’s onto the care team; the care company and the Surgery; the Frailty Team, I want my mother to have her hair washed and shower twice a week; walk down the garden, you know, and oh my god, how do I deal with all of this, you know. But over the months its just, it takes a while to settle down and for everybody to get to know, to get to know one another and to get used to I think. Nothing is ideal put it that way. You’ve got an idea in your head what you’d like but it’s nothing like that. how, um, coming to terms with it is that I know that somebody is in there making, each day, each morning making sure he’s not on the floor; he’s not fallen over.

I know it could happen when they walk out the door, but he is, he does have a Fall Pendant there, not that he wears it all the time. And the Carers and myself shout at him for not having it on, but he’s got the Careline on his wrist and he’s got the Fall Pendant. Um, and they come in in the evening as well, and they, they do the washing up; they do; they get his breakfast and hers, if he wants them to. Um, and he is getting used to them and he is, ah, dealing with it better than he was. He doesn’t like it but, and it is difficult to co-ordinate it because there are things that I seen them doing and I think ‘oh, don’t do that’.

Or the washing, they are doing the washing, that was one of my, ‘how am I going to get, what system am I going to get here for doing the washing’. There’s my mother’s washing. She puts it on the floor in the bedroom, I still don’t know the towels, how frequently the towels get washed. They really need to go to the Laundry I haven’t really got on top of that yet. And then all *(name)* clothes are put in with tea towels and her washing, and I think, ‘oh God Almighty that’s not what I would do’, and I have to let go of it. I just have to let go. Because I can’t do, it’s better than nothing, (*yes, of course*) it’s being washed. It’s cleaner than it would be if it was just left (giggle), you know, so, and I can’t be there. I mean my life is upside down as it is, you know.

**Interviewer:**

***And have you ever had to get help, you know, out-of-hours or at the weekend with (name) health or with his Parkinson’s?***

**Answer:**

Um, no don’t think so, no. A couple of weeks ago they went in, what happened there, um, I think he’d, I think that was when the old carousel went wrong and he had taken some, or he’d taken too much medication I can’t remember which. One of the Carers went in, the one that he really gets on with well, and he’d slept all night, he must have fallen asleep in the chair and he was freezing cold and he was a bit worried so, and luckily we were going over there at the time and he rang me through. But, that, it was all a bit like that, that was a Sunday. Um, but thankfully he was okay, but I didn’t know what to do really at the weekend.

**Interviewer:**

***So, if you had any, had a concern or question about his Parkinson’s particularly, who would you contact or?***

**Answer:**

God, what a question. At the weekend I (*anytime*), anytime. Um, I mean, at the weekend it’s a different matter and I guess if I felt it was very urgent, I would phone the Paramedics, I would phone whatever it is, 111. Um, but in the week time I guess I would phone the Surgery, but it is incredibly difficult now to get through to the Surgery even, at times.

**Interviewer:**

***Tell me about your experiences with that***

**Answer:**

Well a few times. It took me a couple of days to actually get through to them because they have a different system. If you want such and such press this and if you want, then you’re on the phone and waiting and waiting and waiting. Um, you just can’t wait, I’m waiting my life away, you know.

**Interviewer:**

***And do you think that’s changed because of Covid, before Covid?***

**Answer:**

Yeah, I think it’s changed because of Covid, yeah. I would say so.

**Interviewer:**

***Yes. In what way do you think?***

**Answer:**

Um, well it’s all these, um. To start with you have to listen to the message about Covid. ‘Do not come to the Surgery blah, blah’ and it goes on and on and on. And then ‘Don’t come if you haven’t got an appointment’, and so it’s very, very longwinded and I guess they’ve got all these different things in place, um, because they’re having to deal with that predominantly.

**Interviewer:**

***Because obviously it changed how you’ve experienced it hasn’t it?***

**Answer:**

Yes, yes. To start with, um, it wasn’t as bad I seemed to be able to get through, through to the Surgery okay.

**Interviewer:**

***Was that before Covid or?***

**Answer:**

At the beginning of it, let’s say last March, April, May time. But lately it’s horrendous.

**Interviewer;**

***And I suppose thinking about before Covid, how easy or difficult was it to get hold of somebody you needed to?***

**Answer:**

Well, um, I don’t know what it was like for him over there cos I wasn’t involved. But for myself, um, in my own Surgery, we had a good system. Um, and, yeah, it was easier, but I mean that’s all completely gone.

**Interviewer:**

***Okay, and I was thinking about, you know, what you’ve done, what you do to help (name) on a daily basis with his Parkinson’s. Um, do you feel overstretched with everything you have to do?***

**Answer:**

Yeah, yeah

**Interviewer:**

***It’s a lot to take on. I’m sorry if this is upsetting. Take your time.***

**Answer:**

I suppose it’s on different levels that it’s affected me. There’s a very deep shock of disappointment in my brother, sister-in-law, and my niece. There’s a feeling of having been abandoned by them. Ah, and that’s accompanied by anger that I have to really try to set aside. Ah, because I wasn’t, they all knew that my own state of health wasn’t good anyway last year because I’ve had this balloon compression for the trigeminal neuralgia.

And with the stress that it’s been, over this last year, where I’ve had to deal with more and more and I mean it’s sometimes, cos it’s been, it feels like the whole week is taken up. Because it never leaves your head, you know, the concern of what’s going on over in *(local town)*, for both of them really, but *(name)* certainly, it never leaves your head. And there’s always something to be thinking, ‘what have I got to do next’. I’ve got to hold it all in my head because, err, not just on the health side of things.

Where his health has been deteriorating, he’s, he’s, um, neglected the home so there’s a lot of maintenance to catch up on. Big jobs that I have to try and get workmen in to give quotes, and that sort of thing and it all takes time, and you can’t get the men; the men can’t get the materials and that. and it’s just that side of things has been incredibly difficult, incredibly difficult. And my other brother who’s, who walked out on it, walked out on me let’s say, um, is a builder himself, and, anyway. So, you know, there’s, there’s that level and there isn’t anybody else in the family here, that live in (*local city)* cos my oldest sister, she’s been shielding because she has Asthma. And my older brother, he’s ah, in his 80s although he’s incredibly fit but his wife she has Diabetes, so nobody offers to help me put it that way.

Nobody has offered and there’s question marks over why, what has happened to my sis, my cous, my brothers, my sister-in-laws, well it’s, my brother adopted her, my niece. She went and, she was there every week; she did my mother’s hair; she helped lift their spirits; she just stopped, she just stopped going there and, you know, I don’t understand any of it. And I’m left to carry it. And the other thing is that, there are times, and I know that *(name)* my other brother it made him very upset to see *(name)* um, deteriorating, and that’s very hard. Very hard to see him.

**Interviewer:**

**Do you monitor his Parkinson’s (do I)? do you monitor his Parkinson’s?**

**Answer:**

In what way?

**Interviewer.**

***In whatever way that you’ve noticed his symptoms, or you know, what do you?***

**Answer;**

I’m trying to. Just let’s say – visually, intuitively, um, ah, um, mood wise, um, but it’s, its, but some days he looks very poorly and err, um, other days he’s not too bad. And I suppose for me, I have always been the one that um, looked out for him and it’s very sad to think that he’s suffering that, from this illness. And he’s not had a life, and he’s not likely to have a life.

**Interviewer:**

***It’s very difficult to cope with. And, you know, obviously you do so much more for (name) and what do you think helps you cope with issues like medications, appointments and dealing with his care. What helps you manage that?***

**Answer:**

Ah, well I’ve undertaken to do it and I wouldn’t, there’s no way I would walk away from it or let him down because he hasn’t got anybody else to help him and I’m not about to walk away from it so, ah. What worries me is anything stops me from, err, being able to do it, these, this last time month I haven’t felt very well at all, um, so well I don’t know when they’ll be a time, I do need to address err the medication side of things. If I wasn’t able for any reason, to err, not be able to cope with, not being able to do it.

**Interviewer:**

***So, do you go, you know, so you said, the carousel is weekly, so you said***

**Answer:**

Yes, I, I will be over there. I’ve been trying to, to cut it down to once a week. I don’t think once a week, err, is possible really. It’s more like a couple of times a week because I also, I don’t seem to be able to let go of the shopping side of things either. Because they have, into the Care Plan, they have built in a couple of hours on a Tuesday for the Carers to go shopping and it’s only a couple of times it’s actually been successful because, um, they have certain foods by … They’re vegetarians, same as me, and you know, I’m buying things and I want to make sure that they get some decent stuff and the right stuff. And I haven’t got round to yet to putting up a list, but they do know, by looking around, by looking in the fridge and freezer, but I am getting a shop and I am leaving a little list for the Carers to go and get some. So, I’m trying to, by getting the shopping and the carousel then. And each time I go over there, if its for anything else, like meeting a Tradesman, um, I’ll update. I’ll put the medication out, I’ll, so I know that there’s a week there. I do each time I go.

***Interviewer.***

***And how do you get the prescriptions?***

**Answer:**

They ping me. The tell me, each month, now. Then I err, go, and stand in the queue.

**Interviewer.**

***Is that at the Pharmacy?***

**Answer;**

At the Pharmacy.

**Interviewer:**

***How easy was that to set up. How easy or difficult was that to set up?***

**Answer:**

Very good. They did it for the, a lovely, lovely helpful woman in the Boots right at the Surgery. (oh right, yeah). Yeah, she’s fantastic that lady. She set it all up for me. Um, and I have looked at getting it sent to me so, but I just haven’t done these things same as I haven’t set up click-and-collect from Sainsburys that kind of thing. That would save me actually going and doing, it would all be ready for me to just pick up. I just haven’t done it because, I’m trying to live my life, which we’ve got hardly any time to do and I live in a terrible muddle. I’ve lived in a terrible muddle for 20 years; we’ve been renovating the place and it’s still not done. I haven’t got a living room, you know, and this is what the stress has been so enormous. Trying to, trying to get all our stuff done

**Interviewer:**

***And I know you mentioned you had, had trigeminal neuralgia, do you have any other medical conditions?***

**Answer:**

Um, what else. Err, the worse, I think the most disappointing is the amount of, of, of the balloon compression left me with so much numbness in my face. Its made it so uncomfortable, and it’s just my face alive with, you know, underneath its horrendous. Um, and, I don’t know when the, when I’m going to need to have it done again. When the pain is going to come back,

**Interviewer:**

***And what do you do to manage your, your health?***

**Answer:**

Um, I haven’t done very much at all. Before, before this happened, over the years I been trying to do um, a little bit of Meditation and I’ve got a Relaxation Tape, you know, healing your body tape. Not tape, DV, CD. I’ve been trying to do that, and I was trying to err, do walking and that kind of thing, but of course the weather affects my face. And I haven’t done anything at all, very much at all. I am really very, I don’t feel very well at all

**Interviewer:**

***Do you take medications?***

**Answer:**

No, not at the moment. Not at the moment. When I do, the medication for the trigeminal neuralgia, the anti-epilepsy medication. Neurology was what I was trying to say to you before, Neurology at *(city hospital)*. (*okay yes) (Neurosurgeon).*

**Interviewer:**

***So, you go, so you go to (city hospital) (yes) for your appointments, yeah. And do you think your health impacts the way you look after (name) and his Parkinson’s?***

**Answer:**

In what way?

**Interviewer.**

***Does it affect your ability to look after (name) in any way?***

**Answer:**

In the last month, in the last month that I’ve, I’ve just. At the moment all I want to do is to go home and go to bed. I think I think I kind of, I think I’m, what worries me is that I’m going to just completely fold up, you know, and not be able to do anything. I’m a bit anxious about it. Um, but I try not to let it impact on how I look after him. Um, he, he is, you do get very frustrated with him because he’s a very negative person and it’s very tiring trying to keep on spurring him on all the time. Um, because you know full well, um, that he does struggle, he does struggle with doing anything for himself. There’s, there’s an expectation for *(name)* of, um, everybody doing everything for him, within the family. And um, it’s still there so ah.

But my youngest sister she comes down from London. Now the difference between her and I. At the dinner table for example, I mean I’ll go and cut his food up for him cos he struggling with eating his food so I’ll cut up the, ‘leave it’, she says ‘leave him, let him do it himself’. You know, or, she won’t have any, she says I’ve asked him to make me some food and he won’t make me any food and there’s me making his food. It’s the complete opposite. Because her experience, her relationship with him is totally different.

**Interviewer:**

***And do you monitor his diet. Do you monitor what he eats, and cutting up is that something that you’ve noticed you’ve had to do for his Parkinson’s?***

**Answer:**

I have lately. Um, because I’ve noticed that he’s struggling more with um, with the eating. With the, with the Ready Meals that come from (food company). They’re cooked on the day, they’re very nice meals and um, err, I get him the softer ones. He’s just using a spoon at the moment, but on a Sunday, a couple of Sundays, he has a couple of roast potatoes in there. I was there on Sunday and I just automatically cut them up, you know. I think, well I’m here, he’s struggling, what’s wrong with me, and I ask him if he wants me to do it first, um, because there are things that, um, he want to keep doing himself, obviously (*of course*).

But I mean, I, I, remain hopeful that he can, that he does get inspired by some of us, you know. My younger brother that lives in *(city name)*, he, he’s trying to come down. He’s a medical person. Um, he’s trying to come down much more frequently cos he’s retired but he still works a couple of days. He works in Research, but, in one of the Hospitals in *(city name).* Um, so he’s, and he *(name)* gets on incredibly well with him.

**Interviewer:**

***And just thinking about your experiences so far, are there ways that you think the Healthcare System can try and help what you’ve experience and how we could make it better for you, someone who looks after someone with Parkinson’s?***

**Answer;**

Don’t know. Gosh that’s a really difficult one to think about. How, how, I, I think I do, as I do know what it was like before last year, and before Covid, and but I do know that *(name).* I think he came here to the Day Hospital for an exercise class. I think the input in that respect, um, would be helpful, um, for somebody like him. And the trouble was that I, I do believe, he’s a difficult, he’s not like your ordinary person, he’ll, I think it was somebody, the Nurse that ran this exercise class said something and he never went back to the class. And it is incredibly helpful.

But other than, I mean, I don’t know. Those kinds of things to keep a Day Hospital, so, something like err, Arts and Crafts kind of thing, I don’t know. But not everybody would respond to that would they? *(no*) and I don’t know apart from, and your talking about how it could help a Carer, I suppose the thing is that, like I said before, there always on your mind and you’re always worried, ‘have they fallen down; are they okay; is there water around; the kettle; are they making a cup of tea alright? Haven’t blown themselves up?’ or anything like that. Um, um, its kind of, so that your mind can be settled knowing that they’re safe, but I don’t know how.

I mean you need more Nurses to keep popping in and out all the time, but then when people go out the door something could happen, you know, so. I think that what I’ve seen that’s been on offer, through different services, once they’re up and running, is, is very good. The, one of the physios, the physio that saw him over at, this last time up at *(care home name)* she was telling me about the um, PD Warrior Class that they were hoping to set up at *(local hospital)* and that was, they were going to use the PD Warrior exercises because it’s a mind/body thing and I think that would be very helpful because the mind is very affected by Parkinson’s.

That’s that’s another thing to, that’s upsetting to see him. Because the mind itself is affected, I’m only guessing it’s the medication that’s, I don’t know, or. I suppose maybe, perhaps, do they classes for Carers to understand Parkinson’s and how it, whether their Dementia, recognising different stages of Parkinson’s, you know. If there are any signs to show they’re going into Dementia, because that’s part of it as well isn’t it. Because he’s had really nasty hallucinations, and that was very scary. That was very, very scary. He had such a bad one that he called the Police *(oh right*). He thought he saw my brother; his throat being slid (oh dear). It was a very bad one, yeah. (very distressing) yeah, yes. He does have these, so it’s understanding that, those things. For me, I just go onto the computer and look it all up and find my way through it like that. And it talks about it in some of the booklets I got.

**Interviewer:**

***Having the information***

**Answer:**

Having as much information about it. I don’t know how much more the NHS can do. The NHS is struggling along as it is, one way or another, and especially if they’re going to start getting rid of Doctors that come from abroad or.

**Interviewer:**

***Policies are, I leave the policies in our country to someone else.***

**Answer:**

But you know what I mean. Its, you look around and you feel as if your life is chaotic, and then you look into the NHS and I feel that I’m working in it because I’m, you know, connected with what’s going on with (name) and I’ve got a nep, my nephew is a Doctor as well. My Niece is, in France.

**Interviewer:**

***Is there anything else that you’d like to add that we probably haven’t covered about, you know, looking after (name) Parkinson’s. anything else you can think of?***

**Answer:**

I suppose, for myself, I never imagined myself to be in this position, whether or not other people say that or feel like that, I don’t know. But for myself, I never imagined that I would, that I would be doing this. Um, especially at a time where I need my energy for myself so I have to, I don’t have to do everything I know but I suppose you realise how, how very, how very um, difficult it is looking after somebody who is ill, who’s got something that is degenerative and you don’t know from one day to the next what may happen to them. It’s the unpredictability of it. Um, and I, err, I don’t know.

I wouldn’t have, I would have hoped within my own family that I would have had a bit more support. I’ve had support from those siblings who are further away; London and Wales, you know, and my sister, she’s gonna, she had a stroke so, you know, um, its all very difficult. But you don’t imagine yourself struggling along. I couldn’t do any of this without my partner.

**Interviewer:**

***It’s you having support yourself is, is, has been helpful. Much needed by the sounds of it.***

**Answer:**

Yeah, yes. I think, yes, that would be a main point is, is knowing that there are people out there. If you like the NHS people, all of them, that they are there for you and they have all assured me about that. Um, the only um, the only thing that, that um, was just recently where I felt um, not supported by *(GP name)* was when I was very angry about the Doctor coming to give (name) the second vaccination.

I was very angry about it because I feel that the first one was the cause of him collapsing because it was within hours of him having it, and he could have died. And the Doctor came and gave him the second one and he was poorly and then on the phone the Doctor, his Doctor said to me about, and I did say how I felt about the vaccination, and um, he was quite abrupt to me and he, he said, it was like a threat, he said about a booster one in the Autumn.

We might have, the only thing is, there might be a booster one in the Autumn, and I might have said something about I’m not too, well he said, ‘then we may well have to look at best decision’. No sorry, ’we may well have to look at best interest decisions there then’. In other words, I’m going to override your Power of Attorney and do it anyway whether you like it or not. And I felt very disappointed in him; very disappointed in him. But, that’s, its, everybody’s got their own opinion about what’s going on at the moment. Um, and *(name)* would probably want the booster anyway so, that’s how he feels about it. I haven’t asked him about the booster. He’s had the other two and he’s glad he’s had them he says. So you know if he doesn’t, doesn’t worry about conking out and dying from it that’s up to him but as far as I was concerned it was horrendous to see my brother on the floor with a heart rate of 30 something. You know, rushed off to hospital within hours of having that wretched thing stuck in his arm.

**Interviewer.**

***It must have been difficult***

**Answer:**

It wasn’t good. It wasn’t good but I felt talked down to, that was the only time I was very disappointed in that. Everybody else, they’ve been most concerned about, just, about how I’ve been coping um, because of the amount of work I’ve had to, to start with, you know, but its just continued. But I think it is easing off now, but it was just that last year everything had to be put in place

**Interviewer:**

***It all came at once.***

**Answer:**

It all came at once and, unfortunately, historically lets say, in my family, everybody’s seen me as the one that does all the business stuff, you know, and can do this and do that and knows about this and knows about that. Cos I worked in an office but, I didn’t work in an office for all my life, I did for most of my life but the last 17 years I worked in Psychology, you know, for the NHS. But they still see me as this kind of person that can deal with authority and knows my way about, dealing with those kinds of things like Power of Attorney and such.

**Interviewer:**

***Thank you very much for your time, it’s been very helpful.***