# Interview with C08\_01112021

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| * Caregiver of husband with PD dementia * Dementia main issue in caregiving |

**Interviewer:**

**Now I’d just like to start by asking, you know, some generic questions about (husband’s) Parkinson’s. How long has he been diagnosed for Parkinson’s?**

**Answer:**

Well, we think it must have been about 2017, um, that they, we. He wasn’t very well in his health, and we just kept going from Department to Department to Department, and finally they suggested, um, the Dementia. And this lady interviewed, or asked him some questions, and then she said, ‘just take a walk up there’. And she said, ‘oh, he’s got Parkinson’s’.

**Interviewer:**

**Who was that?**

**Answer:**

Can’t remember what her name was, but it was (PD specialist) Department, but it was a lady that we saw. Um, and she said, ‘and look at his face’. ‘Yeah’, I said ‘I look at it every day’. So, she said, ‘can’t you tell how straight and stony it is?’ And like, you know when you’re living with someone, you just accept it don’t you every day, you know. Your features change and you don’t take any notice. And I said, ‘yeah, I have noticed it’s expressionless now’. Um, so she said, ‘that’s Parkinson’s he’s got’. Oh, I thought, ‘oh, okay’.

**Interviewer:**

**Do you know much about Parkinson’s?**

**Answer:**

Well, I know my, err, daughter’s husband’s dad’s got Parkinson’s, but his is very much different to (husband’s) Um, cos (husband) got more Dementia now than Parkinson’s. Um, his, he had his, oh I suppose about 6 or 7 years before (husband) was ever mentioned, um, and as I say his is purely, um, likewise. He never really smiled. Um, his, um, whole outlook on life was very bawdy, um, and never um funny cos he was a Vicar as well. (giggle) He seemed to put on an impression when he was in church, but when he came out of church he was a different person. Um, but, yeah, he has purely got Parkinson’s, um, whereas (husband’s) gone to the Dementia side.

**Interviewer:**

**And how did you find out information, obviously you, I know you, did you look up information?**

**Answer:**

Yeah, yeah, look up information and you just, err, like, (PD specialist) says something, you know. ‘He’s got Parkinson’s dementia’. You go round to his local Doctors and his Doctor’ll just say, ‘he’s got Parkinson’s’. Err, you talk to (PD specialist) and he says, ‘he’s got Parkinson’s dementia. Um, and its funny how some people don’t look at the bigger picture, and I feel that he’s got so much more Dementia, um since it’s moved on. Since the years have gone by.

**Interviewer:**

**What has your experience been from that point of view?**

**Answer:**

That he, he just doesn’t, um, the things that he’s always done for years and years and years, he’s just forgotten. He just doesn’t, um, but I say,’ you’ve done this for years (husband), why have you just, now why can’t you just so it’. ‘I don’t know’, he says, ‘I don’t know’. So, I definitely feel that, um, you know, his whole state of mind, um, seems to have changed completely. Um, you know, right or wrong, but that’s what I feel. Its, and (PD specialist) says the same, he said, ‘yeah, I think he’s gone into the Dementia side’.

**Interviewer:**

**And how long has that been going on for?**

**Answer:**

Um, the last couple of years I’d say. Um, maybe, he was like it before lockdown thankfully, otherwise I’d have said it was because he couldn’t go, couldn’t go where he wanted to go. (giggle) You know, so I’d say, 2 years going on 3 myself.

**Interviewer:**

**And, you know, with all the information. Was it that you looked up or?**

**Answer:**

Yeah, yeah, yes I

**Interviewer:**

**And how easy or difficult has it been to understand information about Parkinson’s?**

**Answer:**

Um, well, I find it quite difficult because it’s like when he first had it, um, he got loads of booklets given to him about Dementia and Parkinson’s and Lewy Bodies and all. All the things that can happen. But you just think to yourself, but is it? You know, you’re always thinking, ‘but is what he’s got or what he’s doing, a fact, is it really that, you know?’ But um, yeah cos when we first came here and they changed (town hospital) into that Nursing Home, and just in front of the Hospital, um, we went there for a, um, Dementia, um, explanation, you know, and you could actually feel.

They told you what you would feel, and they dressed you up. They put these funny glasses on that saw, saw things at this angle and you couldn’t hear very well, and you had to wear these shoes that were very painful. And I found that quite interesting. Um, so yeah, you know, you put bits of that into what you think he’s got now. Um, it all helps to know what they’re feeling.

**Interviewer:**

**And how easy or difficult was it getting information about Parkinson’s?**

**Answer:**

Um, I thought it was quite, quite easy. I mean, as I say, we got a pile of booklets, pamphlets and that, um

**Interviewer:**

**Where did that come from?**

**Answer:**

I think that came from (town hospital) .

**Interviewer:**

**Oh, okay, it was given to you**

**Answer:**

Yes. So, you know, if you were worried about certain thing, you’d just get the book out and find a page that had some, and it puts your mind at rest I think.

**Interviewer:**

**And what about looking for information yourself, do you do that often?**

**Answer:**

My daughter often does (giggle). You know, I

**Interviewer:**

**Does she tell about it or?**

**Answer:**

Yes (okay). She’ll often send me a bit that, ‘oh mum this might interest you’, but you know I just take life as it comes I think to myself. Sometimes you want an explanation as to why he’s doing something, um, but I don’t particularly want to look forward to see what might happen.

**Interviewer:**

**So, you, less about the future is helpful for you**

**Answer:**

Yes, yes

**Interviewer:**

**Okay, and um, you know, does he have any other medical conditions other than his Parkinson’s?**

**Answer:**

No, no, no I don’t think he ever. When we moved he, we’ve only been here 10 years. But when we moved here, we were, first 6 months of being here we were out every day. And all of a sudden one day we felt, think we have to stay at home and start doing some work now. Well, the house was only 2 years old, so there wasn’t a great deal to do, but you know, you have to feel that it’s your house and you’re not just on holiday. I think that’s what we thought, we were on holiday. (giggle)

**Interviewer:**

**Okay. And I suppose what is your role in, in helping (husband) with his health. What do you do?**

**Answer:**

Well, I do most of it now. You know, like I’ve, that’s why my daughter comes over cos, um, she feels there’s jobs that she can do that perhaps I might fall. I’m the clumsiest person going, so it’s not the best will in the world for me to be climbing ladders. But back when they were here last week, we pulled the curtain, and we’ve got one curtain there but this one, the whole thing, came crashing down. Well, it was a good job they were here; they put it back up.

But the other day we was just, I was just walking round doing things, and (husband) was sitting down and the curtain just fell down again. So, I said this afternoon I’ll have to get the ladder out and get (giggle) and um. But yes, I, I mean I thoroughly enjoy gardening, the garden’s my freedom and I’ll often go out there and do gardening. My mum always used to say this when she was on her own, ‘you can get lost doing 3 hours gardening; you don’t know where the time’s gone’. Um, so yeah, I tend to do all the shopping; cooking; the washing and the cleaning; the ironing, everything now. Um, he tries to help but, um, sometimes he’s not much help.

**Interviewer:**

**What about the things he does to look after his Parkinson’s?**

**Answer:**

Not much, you have to prise him out the door to go for a walk. Sometimes, like, err, one day he had to go up to, um, the Doctors Surgery to have a blood test and I was doing the housework that morning, so I said, ‘well I can’t just stop what I’m doing’, and he just went off and did it himself. But other days he says, ‘um, I don’t like going out for a walk on my own’, and I have to saunter round so that’s. I’m a quick walker and, it’s so painful that he’s so slow, but

**Interviewer:**

**Do you walk with him in?**

**Answer:**

I do most days, yeah, yeah. you know, we, we will walk down to the shop and just go in and buy one thing, it seems to give my mind something that I’m gonna do, you know. (giggle). Um, but, yeah, I’m always quite mindful of him crossing the roads, whether he’s really thinking about it, whether he’s, moves quick enough that’s the thing. Um, this road just down here, you know, you have to move quick cos the cars come round the corner. Often when they see me guiding him, and his stick you know, luckily they put their brakes on if they’re coming (giggle) but

**Interviewer:**

**Yes, you’d hope so.**

**Answer:**

But um. No there was only one time he went out on his own, and we had a little difference of opinion. Cos I came out here, and err, did a few bits out here, and err, when I eventually came back in he wasn’t indoors. I thought, ‘oh, he must be upstairs’, so I didn’t call out. So, I went back out, and I went out the front and I thought, ‘well, couple of hours has gone by now, where’. And I thought, ‘I’ll go and see what he’s doing’, cos his favourite thing is to sleep. And I came in and he wasn’t here. I stood here thinking; I rang him on his mobile; he didn’t have his mobile switched on, um, which wasn’t very helpful, and I thought, ‘what am I going to do?’ he could be anywhere. So, I left if for another bit; I walked round the street a bit; came back still wasn’t here, and in the end I rang my daughter and said, ‘I’ve lost him’. She said, ‘what’d mean you’ve lost him?’ I said, ‘he’s gone out. We had a bit of a difference of opinion, and he’s gone out, and I’ve been in the garden not knowing he’s gone. And I said, ‘I don’t know where he’s gone.

By this time, it’s about 5 o’clock, so she said, ‘we’re on our way’, she said, ‘but call the Police’. And I thought, ‘my God, really, really’. so, she said, ‘yes, call them. We’re getting in the car now’. And so, I called them, and um, about, she said ‘we haven’t got anybody available at the moment, soon as I find someone I’ll get them to come’. What good they’re going to do coming here I don’t know (giggle), but they did come, and he was just beginning to walk down the driveway. And they said to him, ‘are you (husband)?’ and he said ‘yes’. They said, ‘do you know how worried your wife is, she’s lost you’. So, then I had to ring my daughter and say, ‘its alright, they’ve, he’s just come in the drive and they’ve found him’. Cos they were 10 miles here, so I had to stop them coming.

So, we’re always mindful now that, um, when he’s going out that he’s got his phone and he’s got it switched on. Um, because his favourite thing of him is to go out and he’s not got his phone, or it’s not switched on. So, that is a thing that worries me, that he can go out and it’s not always convenient for me to go out, and maybe, you know, in the afternoon; the weather’s changed or um, you know, I feel he needs to go out most days just to get a bit of exercise, and keep his momentum going.

**Interviewer:**

**Do you encourage him to do that?**

**Answer:**

Yes. Yeah. cos we started off, um, by saying just go down here, down to the end of the road; right down to the Grove, and then come all the way back. Do that twice, and then just go down to the first corner and back and that’ll give him, you know, adjustment to be able to think, ‘I can do this’. He hasn’t got any roads to cross so, you know, we haven’t got to worry about that, or he can just walk straight round, um, in a circle but he doesn’t seem to want to do that for some reason. Um, so, but then, after a while he got bored with just going down there. So, you know, if it’s like today, if it’s nice, I will take him out. Um, it’s boring to me cos I’m a quick walker and I don’t, um, I get bored; I get tired (giggle).

**Interviewer:**

**And he, what about his, um, medications. Do you help him or?**

**Answer:**

Oh, yes, I get all his tablets ready cos there’s been some mixes up. Um, well he will take a wrong tablet at a wrong time, um, and you say to him, ‘you know, what happened there?’ I mean, even now, with his timer box he’s got. Sometimes it’ll go off and he’ll go out to the kitchen, um, and I think he gets a drink and gets lost and takes a drink and doesn’t take tablets. So, I’m always having to look in the little box to, to check.

**Interviewer:**

**You put it in the box**

**Answer:**

Yes. Yes, I do that in the evening so it’s ready for the next day.

**Interviewer:**

**Every day you do that.**

**Answer:**

Yeah, yeah

**Interviewer:**

**And how many times a day does he take his medication?**

**Answer:**

4, yeah

**Interviewer:**

**And do you know what the medications are for?**

**Answer:**

Yeah, (yeah) yeah, know them all off by heart now. (giggle)

**Interviewer:**

**Something you’ve learned**

**Answer:**

Yeah, yeah

**Interviewer:**

**Over the years**

**Answer:**

Yeah

**Interviewer:**

**..Did you used to do that before?**

**Answer:**

No, he used to do them himself but, as soon as it got more to Dementia, you know, he got lost.

**Interviewer:**

**Yes, so you noticed that?**

**Answer:**

Yeah, yeah, yeah.

**Interviewer:**

**He wasn’t able to manage his own medications**

**Answer:**

Well, see again, he’s got. He had a heart, um, problem, so he’s got tablets there as well. I think he only takes one, two that are related to his heart. Um, so sometimes he’s taking just a few, um, other times, then he goes and sees a Doctor and, you know, he’s taking lots. Its best for me to do it and put it in the box, and then his alarm goes off, and then he takes them.

**Interviewer:**

**Yeah, yeah. You’ve gotten yourself into a little system that works.**

**Answer:**

Yeah, it’s a good system, yeah.

**Interviewer:**

**How did you find out about the timer alarm?**

**Answer:**

Well, it was just last Christmas, my son-in-law bought him, we do this little presents you know, and err, he got him one for Christmas (okay) off the internet. And um, we wanted another one cos he has to take one, another one at 6.30 in the morning. Um, he has to have it at least an hour before his food, um, so we bought him another one off the internet so, yeah, they’re quite good.

**Interviewer:**

**And how do you find, you know, helping him with his medications?**

**Answer:**

I find it’s better. I can do it myself cos I know what he’s got there to take then, yeah. it’s um. Mind you, there have been times when I’ve been out in the garden and the thing’s gone off and he hasn’t heard it cos he’s asleep. (giggle)

**Interviewer:**

**So, it’s constantly checking to see the timer..?**

**Answer:**

Yeah, yeah, constantly looking.

**Interviewer:**

**And how did you manage his prescriptions for the Parkinson’s?**

**Answer:**

Well, we, we belong to this, um, postal one. Um, funny enough just got a packet for him for, um, it’s called Echo Pharmacy now. It’s part of Rowlands I think, chemists. Um, and you, they know what you want, and if there’s anything new then you just. The Doctor writes a prescription; it goes straight to them, um, you know, down the cable, and they get it and post it and it comes to the door, so we don’t have to go to the Chemists.

**Interviewer:**

**Yeah, no, that’s very good.**

**Answer:**

My daughter did all this when Covid started. She said, ‘I don’t want you to be going down the Chemist all the time’. Um, yeah, so it comes to the door.

**Interviewer:**

**Okay. And before Covid you were still going to the Pharmacist?**

**Answer:**

He, he would go to the Doctors; get a prescription; pick it up and just fill it up cos it’s next door. Um, and then come back again so

**Interviewer:**

**Yeah. With Covid I suppose that’s challenging?**

**Answer:**

Yeah

**Interviewer:**

**And, you know. What about your, you know, the Healthcare appointments that you’ve had, that he’s had with his Parkinson’s. what’s your experiences been of those?**

**Answer:**

Well. They’re fairly doable. As I say going round to (local hospital) is easier but getting into (city hospital). I mean it was alright before Covid came, because we got the Red Bus that stops just down the road here on the corner and that goes straight to (city hospital). But cos while we haven’t been doing buses, it’s a bit more difficult. So, I mean like last week he had to go to the Hospital on Monday and Wednesday, so my daughter was only over her, and her, um, husband, only over here for Sunday and Monday, um, but they had to stay the extra time to get him to the Hospital, because, um, be can’t manage it there and back. Um,, while we’ve used the bus once or twice, to get him somewhere, it’s not something at the moment that I feel very safe in doing.

**Interviewer:**

**Do you both then drive?**

**Answer:**

No, no. I gave up driving when I left work so, and like when he, err, had Dementia I could see the way he drove that something was wrong. In fact, one, before he was diagnosed with it. We were going on holiday and we, we sort of driving to the airport, um, at about 1 or 2 in the morning. Um, somebody came up on the offside of him and, he was a bit concerned. Cos, you know, you hear these things, don’t you, where they force you off the road and take your car and you’re left standing. Anyway, um, he, after a little while this person went off the slip road, and then within a few, err, minutes a Police Car was behind us.

So, um, he stopped him, and he said, ‘um, he wanted to know if he’d been drinking’, you see. So (husband), I was still in the car and (husband) said, ‘no, I’m going on holiday’. He said, ‘I’m driving to the Airport. So, he said, ‘Only’, he said, ‘just, we had somebody following you a while ago, and you seemed to be weaving, um, a bit, and we just wondered whether you’d been drinking’. He said, ‘I can tell by talking to you, I can’t smell alcohol or anything’. See, but that’s how, another thing how it started. And I’d always be saying to him, ‘you’re too near the kerb’; and then it was, ‘you’re too near the middle of the road’. He would just wonder.

**Interviewer:**

**Yeah, yeah, yeah. So, this was before his diagnosis of Parkinson’s?**

**Answer:**

Yes, yes. Yeah, so, he, after a year the, like, he had to let the. When they told him it’s Parkinson’s he had to let the DVLA know, and they put him on a yearly Licence. And then he had to have a test. And he did pass the test, although I said to the lady, ‘it’s not safe for him to be driving, I’m really, really worried for other people’. Cos when he wonders near, you know. We had to go to my daughters’ one day, she was on holiday and we went over there for a couple of days to look after the house. And um, he touches the kerb, well, you see, if that throws you back into the middle of the road, you could kill someone.

And I said to this lady, ‘I’m really not convinced that he should have a Licence’. I said, ‘I know he really, really wants to drive, but the car’s sat on the drive most of the time;’ he didn’t use it, but he didn’t want to give up. So, um, he did pass the test but then he gave up driving because we were all, um, you know, frightened for him, and for other people. Um, and, you know, it couldn’t have gone on much longer; the car sitting on the drive. There was no point in paying for it, so

**Interviewer:**

**Do you go to his appointments with him?**

**Answer:**

Yes. Yes, because I, um, I like to know. If not he comes home, um, and he tells you something and you think to yourself, ‘that don’t sound right’. He come out of the Dentist one day, and he’d only been in there; had a check-up and then they were doing something else. He was only in there about 20 minutes, and he came out and he said, ‘I’ve had 4 fillings’. I said, ‘you can’t have had, you haven’t been in there long enough’. But um, it was just the way they told him something, and he came out and he got it all wrong.

So, um, when he had this stomach x-ray thing the other week, um, the lady said to him, ‘you could have Diverticulitis’. So, we were waiting in Tesco’s car park because of the state of the, um, Hospital now. So, it, well, they’re rebuilding the (city hospital) (oh yes). So, he said he’d walk up there to meet us. So, he walked up there, and he couldn’t think of the name of what she said he might have (giggle). It was a guessing game all the way home (giggle)

**Interviewer:**

**Yes of course. Um, so have your experiences been for instance with the Parkinson’s team specifically?**

**Answer:**

Um, quite good. But I think to myself, um, there’s been occasion when I’ve rung up the Parkinson’s Nurses and they’re not there. You wait for them to ring back, and they ring back when you’re not there and when you do get through there’s not, not much satisfaction, you know. Um, so, I s’pose there’s not a lot of people can do it. It’s like when you go up to see (PD specialist), you know, you tell him, he asks you the same questions and you tell him the same answer, and you come out saying, ‘well, what was all that about’. I suppose there isn’t much else they can say at the moment, or do, um, but I suppose that’s life, you know. It’s like having any other illness I s’pose, you just, you just, you know, carry on don’t you.

**Interviewer:**

**So, I suppose you feel at times nothing’s changed, or nothing’s come out from the appointment?**

**Answer:**

Yes

**Interviewer:**

**Nothing you found useful or helpful**

**Answer:**

Yeah

**Interviewer:**

**And what sort of things, you know, do you contact or speak to them about that’s you know**

**Answer:**

Well, if there’s a problem with tablets we’ve often got onto the Parkinson’s Nurses, and they will sort out that. Because I mean, obviously (PD specialist) has got his list of people he’s got to see so, it’s not easy to talk to him, but the Parkinson’s Nurses will sort out if there’s a tablet issue. Cos when he first started to go on to the, err, Parkinson’s tablets, um, they used to make him, um, have hallucinations in the night, and he was up walking about, you know. And because he couldn’t sleep, he slept in the day, but um, they suggested maybe if he has half-an-hour at lunchtime sleep, because his sleep was so disrupted. But as times gone on he’s gotten used to the tablets so, and they’re not too bad now.

**Interviewer:**

**And have you, has there been changes about his Parkinson’s medications at all?**

**Answer:**

Not a great deal, no, no. No, it’s basically been the same tablets but, just increased. He started off by 3 a day, and then it went up to 4, and then when we saw (PD specialist) last year, he said if he can tolerate having another one twice a day, do it so it’s like he’s having 6 a day now. Um, because he couldn’t, for a lot, for a while they took him off those tablets and but him on another one, and that really made him hallucinate. So, they put him back on those ones.

**Interviewer:**

**And how have you found managing all the changes in the medications?**

**Answer:**

Well, you just get used to a system, and then it changes. Cos like when he goes up about his heart, they seem to have got it on a level at the moment, but he had, err, atrial fibrillation

**Interviewer:**

**Fibrillation, yeah**

**Answer:**

And every time they did the technique it didn’t work. So, he had that done 5 times in all.

**Interviewer:**

**The ablation?**

**Answer:**

Yeah, yes. And when it, they had it, they did it the last time, he was only taking one heart tablet. And then, gradually its increased and increased, and then it still wasn’t working properly. You know, you had these, cos of Covid, you had these over, over the, um, telephone conversations. Um, but they’ve put him on this one now that they seem to have left him on so (giggle).

**Interviewer:**

**Lots of changes**

**Answer:**

Yeah, yeah

**Interviewer:**

**And um, how about your experiences, you know, with your GP. Do you see your GP, his GP for his Parkinson’s?**

**Answer:**

No, no we don’t, no it’s just (PD specialist) we see, yeah.

**Interviewer:**

**Yeah, that’s fine. And um, were there, how has that changed with Covid seeing the Parkinson’s team. Has that had any impact, um Covid with appointments?**

**Answer:**

Not really. I think, um, we, I think we may have. I think we see (PD specialist) about every 6 months, so I think we only probably missed out a couple of appointments and things were going along okay, so (stable) yeah, yeah. so, yeah we didn’t feel as if as if there was no-one we could turn to, yeah.

**Interviewer:**

**And have you had any, you know, contact to other Healthcare services for his Parkinson’s, so Physiotherapists, Occupational Therapists or Speech Therapists?**

**Answer:**

Um, no. As I say we had a couple of, um, Nurses from the Parkinson’s team that, Therapists that, um, gave him some advice, but no we haven’t used anything else like that.

**Interviewer:**

**Okay. And have you had any issues needing to get help out-of-hours or at the week-end?**

**Answer:**

We did once. I can’t remember what that was about. We needed some help and, um, it was the weekend and no-one was working so we just had to bobble our way through it, you know, and. I can’t remember what it was that. It might have been back when he was having hallucinations and that, you know, cos I found that quite disruptive. He was walking around half the night and I wasn’t getting any sleep, but he could sleep, sit and doze and sleep all day, you know, and I couldn’t. so, that was quite traumatic. That’s where my daughter comes in, she, she takes command and she says, ‘right, you go and do this, and you can do this’. Yes, so, she knows exactly, it’s not like I have to go to her and say, ‘oh, its dreadful when he does this or he does that’, cos she knows what it’s like when she stays. She stays overnight and goes home the next day.

**Interviewer:**

**Yes. Does she live nearby or?**

**Answer:**

No, well she lives in (city) which is about 50 odd mile away. So, she’ll come over on a Wednesday, and she’ll just go home Thursday lunchtime so she’s home for her, her boy. He can do without her one night.

**Interviewer:**

**And she does that every week?**

**Answer:**

Every week, yeah.

**Interviewer:**

**And um, you know, I suppose thinking about, um, you know, the things that you do, um. We talked about medications, appointments and getting him out for exercise. Is there anything else you do to help with his health with Parkinson’s?**

**Answer:**

Try to make him drink. (giggle)

**Interviewer:**

**Tell me about that**

**Answer:**

Well, because he will only, you know. It’s like breakfast, lunch, dinner we have a drink. Trying to get him to have a drink in-between. He will drink, but you just have to keep reminding him. It’s not, it doesn’t come, I mean I can be working out in the garden. I can be out there all afternoon; don’t get a drink cos he doesn’t have one himself.

**Interviewer:**

**So, you watch his hydration as well?**

**Answer:**

Well, I try but, you know, you say to him, ‘go and get a glass of water’. He comes out to his bottle thing and has few good lugs, and he pours out a glass of water. But um,

**Interviewer:**

**And what about diet or mealtimes is that something you**

**Answer:**

Yeah, I do all the cooking and um, decide what we’re going to have (giggle).

**Interviewer:**

**Has that changed with his Parkinson’s, has his Parkinson’s changed him?**

**Answer:**

He used to help me get the dinner ready, you know, cos we have lots of vegetables. It’s, I don’t buy ready meals or, it’s maybe just a Sunday that we have something out of the. Like yesterday he had a pie, and I had my cod fillets. Um, or he’ll have a piece of chicken. If not, it’s just things I cook myself like a curry, a bolognaise or a,

**Interviewer:**

**You haven’t had to change that because of his Parkinson’s?**

**Answer:**

No, no, no

**Interviewer:**

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

**Answer:**

Um, well as far as it goes, you know. I mean, I, what do you mean monitor it?

**Interviewer:**

**Anything that you, you notice, or do you look up his symptoms or how he responds to medications or**

**Answer:**

Well, you know, sometimes he’s walk, he’s standing there, and he just stands. And he’s got his hands in his pockets and, you know, if it was somebody thinking about something you say to them, ‘what you thinking about?’ And they would say, ‘I was thinking about how to do so and so’, but he’s not thinking at all. He’s got a complete blank. I try and interrupt with those moments because, you know, the more you go off into a blank the more you’re going to get used to blanking.

**Interviewer:**

**Yeah, yeah. And, um, do you notice if he’s missed his medication or, you know, the effects of his medications?**

**Answer:**

Funny enough I came back. Cos of a morning I normally go for a walk. Because I’ve had this cough I haven’t been going, but I will go for about a 10 mile walk before breakfast. And I came back, and I say to him, ‘right’, so he said, ‘I’m a bit confused’. I said, ‘confused about what?’ He said, ‘um, I was going to have porridge for my breakfast’, he said, ‘but I’ve forgotten how to make it’. I said, ‘how can you forget?’ He said, ‘well’, he said, ‘I know you get the oats out’, he said, ‘and then I’ve forgotten’. So, you have to make him things then, it’s no good telling him what, you have to make him things. I could tell he was really confused, and I said to him, ‘what’s made you like this today then?’ cos usually morning I find is his best time; when he’s had his sleep; um, and he’s got up; he’s, I suppose his body’s had a relax in bed. Mornings is his best time. I said, ‘so why are you like this?’ He said, ‘I don’t know, I just feel confused’. When I looked in the tablet box he hadn’t took his tablets. So

**Interviewer:**

**There is a difference if he hasn’t taken them, so yeah.**

**Answer:**

Yeah, there definitely is.

**Interviewer:**

**And how do you think his, you know, his memory and Dementia has impacted how he’s looked after his health?**

**Answer:**

Yeah, it’s a lot. I mean yesterday I said to him ‘(husband) when did you last have a shower?’ cos I could see he had the same trousers on that he’d had on for 4 days. So, I said, ‘when did you last have a shower?’ So, I suppose it was, he said ‘it must have been Wednesday’. And I said, ‘you haven’t showered since then’. Cos he always can manage a shower, um, and he can always dress himself. Takes him a long time, but he can always do that on his own, so that’s why I go for a walk cos he can take as much time as he likes, and he hasn’t got me breathing down his neck saying, ‘you can get up slowly and do things slowly. So, I said, ‘right, upstairs, shower’. I said, ‘we always shower every other day, you know that’.

Um, so that’s another thing, I’ve now got to implement again that he’s showering properly. But as I say, he’s got a stool in his shower so he can sit down and like clean himself, and not feel like he might fall over. Um, we are about to try and get permission to do a, um, err, room in the garage, cos we don’t have cars, um so that if it’s ever the case he can’t get up the stairs, then he can use that as a bedroom.

**Interviewer:**

**It’s a bit of planning**

**Answer:**

Oh yes

**Interviewer:**

**Ahead.**

**Answer:**

Oh, yes yes.

**Interviewer:**

**And how, how was that**

**Answer:**

Well, we’ve got an Architect that’s doing all that, cos I can’t do it. I don’t understand the jargon. Um, he’s doing it, and he’s just submitted the plans to the Council.

**Interviewer:**

**How is that, thinking about the future with Parkinson’s. It must be something you’ve thought about**

**Answer:**

It’s, it’s a bit worrying that you don’t know where it’s gonna. Sometimes they talk about Parkinson’s on the television, and they say things and you think, ‘wish we weren’t listening to this’. (giggle) Um, but err, you know, just, just got to take the rough with the smooth haven’t you. I mean when I was told that I had Asthma when I was young, I didn’t think I was going to die but some people can, can’t they? (yes) But, you know, its, I find that he’s got very, um, he doesn’t say anything now.

He used to be the most talkative person, but he’s been going to an exercise. Another thing, when my daughter comes down on a Wednesday she takes him down in the car, err, to (local town hall), um, and they have like a little exercise. A lady that does some exercises for them. And, um, last week was her last week cos she’s developed breast cancer, so she’s got to have an operation. She’s hoping to come back if she’s okay. Um, but she said, ‘come in about quarter of an hour before because we’re just going to have a little drink and a piece of cake’. And we did this, and I was surprised how quiet he sat there; he didn’t say anything at all. And I thought to myself, ‘you know, you’re quite withdrawn’. I mean he doesn’t say much indoors unless I ask him things, and I always say this to him. You know, I’m talking away to you all the time but, unless I ask you, you know, you never ask me anything. You never say anything to strike up a conversation. In fact, sometimes I talk to him and he doesn’t answer me and that makes me really angry. (giggle)

**Interviewer:**

**Yes, so that’s changed with his Parkinson’s**

**Answer:**

Yes, yes. He said, ‘I didn’t think it necessitated an answer’, okay. (giggle)

**Interviewer:**

**And, you know, what is the impact of you helping him, supporting him, had on your life and social networks if any?**

**Answer:**

Well, some days I am running round all day long, and it tells in my sleep. Because I go to bed, and I have about 2 or 3 hours sleep, and my body wakes up. Um, it’s just like saying, you know, you shouldn’t be resting, you known, you should be um, doing. I mean naturally I do things for myself, like I go for this walk; come home; have breakfast, and I’ve either washing or cleaning or gardening or shopping. I don’t go out for much shopping now, cos with Covid I have an, err, delivery come. It’s just the odd few bits that you might want. Um, you know, and then there’s cooking and things like that, and getting meals, but I just don’t seem to stop especially if it’s a washing day.

When my, um, daughter and her husband and the boy was here last week, oh there was so much washing. When they went I thought, ‘I don’t know where to start’. The house was in a mess, I didn’t know where to start and it’s taken me right from when they went on Wednesday, right till Friday to get all the washing. Every time they have a shower they have to have a clean towel. And I think to myself why can’t you detail the one you’ve got and say.

**Interviewer:**

**And do you feel overstretched with everything you do to help with (husband’s) Parkinson’s**

**Answer:**

Um, not particularly because of his Parkinson’s but, um. But like if I go off into the garden I can, I can guarantee that he might be in here sleeping, and I don’t want him to sleep in the day because he won’t sleep of a night. Um, but there’s not much I can do about that. sometimes he’ll come out with me or come out after I’ve gone out just to cut a few sticks or, um, fetch a tool out or something like that. um, he’ll sometimes do that, but I ‘m always thinking he’s going to be sitting in here sleeping.

Um, and I mean that’s the favourite thing, to turn the television on. I find as soon as we’ve had lunch, you know, I’ll fetch him the drink; and we have the drink, and then his brain sort of switches off. I don’t know whether he thinks he’s going to have a siesta but, um, we might have the television on for the news and, um, you look over at him and he’s looking like this. He’s trying not to let me see his eyes are shut (giggle).

**Interviewer:**

**Um, you mentioned earlier that, you know, (PD specialist) thinks he’s got Parkinson’s Dementia, but your GP just labels it Parkinson’s. Obviously there’s, how has the communication, or you know, care been co-ordinated between Parkinson’s team and the GP. How have you found**

**Answer:**

Well, I think (PD specialist) like when he saw us last week always like writes a report, and then passes it into the GP to say what he’s discussed, and, um, but I don’t happen to think that Doctors round there is the best Doctors in the world. I’ve changed from there because I couldn’t stand his treatment, that he was getting, but he wont change because he said all the, err, Doctors he sees knows that that’s his doctor. And if it gets missed out, and I think that’s easy for him to walk to, if he has to go to the Doctors. Cos I’m with (GP surgery name) now. I find them the best Doctors.

**Interviewer:**

**So, you’ve had bad experiences with his, his care**

**Answer:**

Yeah

**Interviewer:**

**In what way?**

**Answer:**

Well, um, they’ll make an appointment, and you can sit in the Surgery, you can sit in the, um, waiting room for an hour. And who want to waste an hour, why can’t, and they never seem to be able to make a decision. And if I go with him, I find that they will. They’re not interested in me; they don’t; they don’t; they, it’s not me they’re seeing or, you know. I do feel that I can say how he is.

My daughter took him round there last week, or the week before, cos his eyes. He’s a problem with his eyes as well, they stream with water just drip. And the Doctor said, ‘I think you’ve got dry eye’, so gave him these eye drops; didn’t work. Cos when you go to the Optician’s or the Dentist they don’t want to deal with him because his eyes are infected. Um, did these eye drops; dry eyes they say, ‘I think this is what it is, dry eyes. Try these eye drops’. You try those, and you go back, and you say, you know, ‘this hasn’t helped’. ‘Well, try these ones then, these are different’. Okay, try those ones. And you know, that’s another job I’ve got, to put his eye drops in 4 times a day. Um, and then they’ll say, um, ‘well try these ones, because if I refer you to the Hospital they’ll ask you if you’ve used these ones’. So, you try those ones. They don’t do any good.

So, they wanted to give him some more, so my daughter went round with him um, and he’d spoken to the Doctor on the phone about his, um, bowels. And she went round, and the Doctor tore her off a strip. He said, ‘you’re here for an appointment for me to talk to him about his bowels, not about his eyes’. She said, ‘I felt so embarrassed’, she said, because I didn’t know anything about this. She said, ‘I didn’t know he’d asked the Doctor about this’. But they have now referred him, he’s got an appointment in March (giggle), so yeah.

But, you know, if you ask him to talk to the Doctor on his own, um, in fact when he’d had these tests, I said, ‘are you sure you gave the Doctor the right information, because nothing you’ve said to me seems to match up with what they’re doing’. So, I don’t know, I don’t know what he said to him so.

**Interviewer:**

**And its, is that because those appointments have been over the phone?**

**Answer:**

No. Well, he spoke to him once over the phone, but the Doctor said, ‘I want to speak to you in the Surgery’. Um, so, yeah, um, he, all what I’ve learnt it, um, he says that he didn’t say he had some of the things, but I think sometimes when they say, um, one word, um, if your memory’s not very good you latch onto that one word. And answer it. I can remember when my mum was getting, um, old, um, you used to say something to her, and she used to rush off to do the job because she’d heard one word – the kettle. You know, she used to run off to do, put the kettle on and not listen to the rest of your information about I’d like a cup of coffee. (giggle) You’d end up with tea or something.

**Interviewer:**

**Yeah. it’s difficult for you to know whether, you know, what he’s told the GPs**

**Answer:**

Yes

**Interviewer:**

**Because of his memory, yeah**

**Answer:**

Yeah, yeah, yeah

**Interviewer:**

**And, um, you know, I suppose, you know thinking about your own health. Do you have any health conditions?**

**Answer:**

I have Asthma, yeah. And, as I say this is why I went to the Doctors the other day, cos I just couldn’t be getting rid of this cough. Um, and the gentleman in the house there, he had Covid a couple of weeks ago and he said, I had to go into Hospital and be on the Ventilator cos I’ve got Asthma. And, yeah, we was talking about my cough, he said ‘you should go to the Doctor because’. I’m not one for going to the Doctors. He said, ‘if you did contact, contract Covid, you know it could be really serious for you’. Um, so, my daughter was here last Wednesday, and she said, ‘you’re going to the Doctors’. So off I went.

**Interviewer:**

**Do you take any medications for your health?**

**Answer:**

2 inhalers I have.

**Interviewer:**

**Yeah. And um, I suppose, you know, what things have, help you, you know, healthwise, to look after (husband)**

**Answer:**

My daughters’ looked after, helped, you know. She, she can work out a lot of things that I can’t work out. Um, whereas it takes me a long time to figure out things that you can do on the computer and that, um, she can do it instantly. And she’s whizzing with her,

**Interviewer:**

**What sort of things does she do that? Medications or**

**Answer:**

No, just if she’s looking up something, like, it could be anything. It might be an aid that he can have that might help him, or. When it was the point of getting all the equipment for him like the stool in the shower, and he’s got a bar on the side of his bed to help him pull himself up out of bed. Um, things like that she arranged with the Council to get all that equipment. (okay) Whereas with me, I’d say, ‘you know, you can manage’ (giggle)

**Interviewer:**

**And have you had any financial expenses with (husband’s) Parkinson’s?**

**Answer:**

Not that. Not until now. I mean changing this room’s going to be quite expensive. Yeah, you know, they send their monthly bill; besides if they’ve had to apply to Council and all this business. And at the end of it you don’t know if you’re going to get it or not.

**Interviewer:**

**But the aids that you talked about, that was through the Council?**

**Answer:**

Yeah, that was through the Council, yeah.

**Interviewer:**

**Did you daughter help you**

**Answer:**

Yep, yeah.

**Interviewer:**

**And um, I suppose, is there anything else that you’d like to add about looking after (husband’s) health with Parkinson’s that we haven’t talked about**

**Answer:**

I just really feel that. I mean, when he first got it he used to go to, round to the (town hospital) and they used to have like little 6-week sessions, where they could, um, get them to walk properly. Um, or do things a different way that would help them; how to get up properly and things like that. Um, and I think, it’s more the reason like why we got him to go to this class on a Wednesday.

Um, it was just something that you felt somebody was doing something, um, and you weren’t just left on your own. I mean I can say to him, ‘come on, we’re gonna do this set of exercises’, but, you know, he doesn’t take a lot of notice of what you say, but if he goes to outside people, he’ll say.

I mean when he gets up out of the chair, um, he’ll wiggle his bum to the end and then he can, if he sort of, get himself up like that, and that sort of things that he’s learnt down there. Um, to sort of get himself up. Cos I think this is, with a lot of, this is not too bad but with like our sofas in there, they tend to slant back a lot. And then you’ve got to have the strength in your arms, if you haven’t got strength, um, to pull yourself forward and then you’ve got to. He often used to try and push himself up like this.

It’s the same as the toilet seat up there, in the en-suite, you know. Um, he’s got a, we actually bought that one cos the one they supplied from the Council wasn’t fit for our shape toilets. Um, so we saw this one and we got that one. Um, but he feels like he can push himself up then. Cos he used to say to the woman that came and assessed, the Therapist, ‘I just hang on to the towel rail’. ‘No, you mustn’t do that’.

**Interviewer:**

**And I suppose, any thoughts about how you think the Healthcare System could be changed to help you, help you manage his health with Parkinson’s?**

**Answer:**

Well, I suppose there’s such a lot of health things isn’t there really. they can’t see to everybody. Um, it’s just something you have to get on with I think. I just dread to think if he was here on his own, um, what would happen.

**Interviewer:**

**Yeah, yeah. But you don’t think there’s anything that the Healthcare System could change to try and help you and (husband).**

**Answer:**

As I say, you know, apart from running some sort of Therapy Class to help them on their, um, on their way but, I think that’s about all cos there, I suppose they’re all so busy, you know. You can’t fit everything in can you, but, um, I think they tend to take notice of people outside more than they do with you at home, you know. They just think, ‘yeah, okay, yeah, yeah.’ (giggle)

**Interviewer:**

**Thank you very much**

**Answer:**

Okay