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**Interviewer:**

**So, what we want really is your experiences of helping mum care for her health with Parkinson’s and your views and how you have learnt to live, you know, and deal with her health with Parkinson’s. The treatments and advice that you’ve been given the last few years.**

**Um, I’d just like to start by asking some general questions about Parkinson’s**

**Answer:**

Of Course.

**Interviewer:**

**How long has she, has mum being diagnosed with Parkinson’s?**

**Answer:**

I think it 2015. It was when she was back in (city) she got diagnosed. She only moved to this area within the last year, so February. So, she came into this area. Mum came to live with me, um, well, during the first lockdown because dad had passed away, so I didn’t think she was coping very well in (city) and I was worried about cases. So, I brought her here for the first lockdown, which was the 23rd of March as I remember. I think it was the day before the full lockdown. And she lived with me for the best part of a year, so she kind of got used to being on one level.

Whereas back in (city), she had stairs to climb and, although they had a stairlift, mum and dad, um, she, she wasn’t too clever, so it made sense. I could keep an eye on her, I was worried for her health back in, um, (city). So, she came and lived with me here, and the whole time she was here she seemed a lot better because I suppose like, she didn’t need reminding of.

We’ve got an Alexa thing, that’s been a Godsend. I just set up all of her reminders on, well she’s got one as well now but, I sent the reminders cos she has to have medication. Now it’s every 3 hours, but at the time it was one dose less in a day. So, that’s how we manage the timings, otherwise she would have forgotten to take the tablets and her mind is getting a little bit worse now. So at least that voice will tell her, you know, ‘take your tablets now’.

Mum’s coping okay, um, but it changes day to day. She has good days, she has bad days, and it was the same when she was here, although mostly it was good days. She could make it into my garden and um, and you know, sit, and enjoy the sun out, with a sun hat outside under an umbrella or something. And she used to help a little bit in the kitchen doing things so, so she was doing really well.

Um, however, we back to (city), um, at the end of the first lockdown when it all opened up and that was when she decided she wanted to come to live near me and she realised that living on one level was a darn sight easier than how she was coping in Surrey. So, she sold her home and err, or I helped her. I went to stay with her while that was happening. We sold her home; she came back and lived with me briefly, um, and put an offer in on a bungalow in (town). And she lived with me again while that was going through. So, for all that time, um, it was a good 6 months in the end, because unfortunately the person who was selling the bungalow passed away, and it took a bit longer. That was fine.

And I could watch mum every day, what was happening and um, she’s not always truthful about her condition. She, she likes to hide it certainly to family when family come and things. And actually, to a certain degree, to Doctors. She would say, ‘oh yes, I’m fine, I’m coping really well’, but the truth is, if I wasn’t there to do certain things for her she wouldn’t cope so well. so, I was quite concerned when she moved in the bungalow, um, as I say in February, but she was a bit better then.

I check on her every day now. We have a phone call in the morning and um, just, and I visit her every other day, at least, sometimes more. Um, there, mostly she’s okay, but she struggles on like day-to-day things like hanging out laundry, stuff like that. Um, bending down she goes dizzy; um, sometimes she can’t do stuff at all. She’s sat in, she gets up, it’s all she can do to take her tablets; sort them out and take her tablets. She’s copus mentus so she can work out what medication she needs but, um, recently she’s getting more vague with it.

And although I’m not at the stage of actually putting the tablet, I am when I’m there, in at at the right time, because she has to have them in the little compartments by 11 o’clock when she’s due to take her second dose. She does the morning dose the night, has it all set up the night before so she, in one of these pill pots, you know, every so many hours she takes them. Um, so, um, she knows what the tablets but she’s having to check and double check, so she’s struggling a bit on that. Certainly, where she’s taking um, 2 tablets, they’re both called Stalevo but they’re different doses, and the fact they’ve got the same name on the box it’s harder for her to work that out you know.

She’s had her eyes tested, they’re’ fine. Making sure that all her medical things are up to date, And I take mum for all her appointments. So, from my point of view, I’m, um, a supporting role if you like.

Um, whenever mother has um, visitors. Um, she had her neighbours visiting recently, she used to love entertaining and it’s hard for her to accept that she can’t do that anymore. And so, she’ll invite people, and then she’ll panic about what she’s going to cook which she can’t cook, you know, anything major anyway. And, um, like I might turn up and say, ‘right, I’ll do a lasagne and you’ve got to provide a salad’, which she can get from a bag, you know, that sort of thing. So, um, if she does a roast dinner for family, she’ll put the meat on first thing in the morning and she’ll peel vegetables, when she’s able to, the night before usually. But to actually cook it and put it together, she can’t physically do that. she’d never admit it, but she can’t actually do that anymore. And, um, so I’m always involved when she has friends, or people round because she just needs an extra pair of hands.

Um, the two times when I’ve not done, because this year I’ve been doing my bungalow, um, I didn’t have a spare room, so as soon as mum moved out into her thing, her place, I was then able to make, start making changes because I’m trying to prepare the second bedroom just in case something happens, and she has to come back and live with me again. Because I’m watching her, and I am worried for her. So, um, I’m trying to make adjustments and, um, I’m going to get an en-suite put in so it’s all one level and a wet room so it’s easier.

Um, I hurt my shoulder last year, during the lockdown from pushing her wheelchair partly, but also because I’m quite physical. I was building a patio and stuff so it’s my own silly fault, um, which meant I was out of action for pushing the wheelchair. So mum was forced into using a walker, unless we had another person around that could push the wheelchair, so I had, because she’s, she’s getting lighter; she’s lost a lot of weight, but originally she was quite a heavy weight. Um, that was, that was hard for me so, you know. They’re the sort of challenges that we’ve had along the way but um, I must admit, um, I ask her now, ‘we taking the wheelchair or are we taking the walker’. Nine times out of ten she’ll say, ‘walker’, which is okay. Um, but, more recently I say, ‘well if we got a long way, we’ve got to take the wheelchair’, and I just tell her to sit in the wheelchair and be done with it, you know. And, and, she, dad was the same he was reluctant to begin with, but um, of course, you know. So, all I, my role really is making sure that the aids are there for her day-to-day; um, liaising with health officials, you know, the Doctors. Mum sometimes gets a bit tongue tied, she’s not very good at expressing, you know, she’s of a generation that is, ‘yes Doctor, no Doctor’, and she lets them say, ‘oh, we’re going to do this’, and that’s fine. But I’m, you know, coming up to 60 next birthday and, um, I’m question ‘why has she been given stuff? Why have you changed this, and things like that, so I kind of do the same for my father, and so, when mum says, ‘yes Doctor’, I say, ‘but you forgotten that you’ve still got this problem and what he’s just said won’t solve, you know, the other problem, whatever it is’. So, sometimes I have to remind her of things. No, I’m quite close, sometimes I feel guilty that I’m mot with her every day, but um, I realise that she, that she should have an independent life. And I think she feels the same for me because when I’m not around something might go wrong.

And the two, well one fall was when I didn’t have my bedroom her, so my daughters came, her grandchildren for a visit and they stayed with her overnight. And I was there as well, but she automatically gets up and wants to serve people. I think it’s a generation thing, you know. And so, she gets, suddenly she’ll get up and she’s got in her head that she needs to make coffee or whatever, but she forgets that she can’t just stand up that, you know, you got to sort of take your time and practice and get your head in the right space before you take off. But she didn’t on that particular time, and um, she had a fall. And she hit her head and she had a horrible head wound, and I ended up taking her to A&E, you know, so, um, that was a bit scary. And that was about a month ago I suppose.

Um, and then, two weeks later, my cousin from Wales which, who we don’t see very often he came. But equally, I didn’t have a room for him because people would normally stay with me and visit my mum, but I didn’t have anywhere for him to stay. And I stayed with them, you know, for the evening and once I go I leave them to it. And then I get a phone call at half past ten saying mums had a funny turn, um, where basically she’s flopped forward and, you know. I don’t know what she was trying to, I suspect she was trying to get up to get something for my cousin, again. And um, that was to do with blood pressure, um, because err, I don’t know the technical names, but I know if she stands up too soon after eating; or if she stands up too quickly without adjusting, then she will go; she will fall over. And, um, she thinks she can do things and she can’t.

And she’s at that stage where she’s learning to accept it now and she walks around the bungalow. I go round there and err, I tell her off because she walks round the bungalow and I say, ‘where’s your stick?’ or ‘where’s your frame?’ Because she, she likes to go from A to B just wandering from room to room. And then she says, ‘I put my stick down’. She’s got 3 walking sticks. Um, and you can ask her when you’re there, well say ‘what do you use’, she’ll tell you a walking stick. She’s got 3 but she loses them all round the house, but, um, the three-wheeler frame, um, she’s forever, you know, got that. But she won’t walk in the house with it, we take that out.

Um, on a really bad day, we’ve got another one with 4 wheels we picked up, I think it was from the Charity Shop can’t remember cos there’s a lot of Charity Shops that sell aids. And, um, it’s got a little seat on it and, um, if she’s having a really bad day I insist that we use that one and not the 3-wheeler, because I know within a few paces she’s got to sit down. So, we still try to do the things but, um, that she used to do, but the truth is she can’t, yeah.

**Interviewer:**

**Sounds like obviously you’ve learned quite a lot over the time that she’s had Parkinson’s to how, you know, things have been and how to manage**

**Answer:**

Oh changes, yeah.

**Interviewer:**

**Do you remember when she was first diagnosed, you know, what information did you get about Parkinson’s or did you have any?**

**Answer:**

Yes we did. the Hospital gave her a leaflet; she had it, it was actually diagnosed. It probably took them 18 months to diagnose it. Mum had lots of different symptoms to start with, um, from bad back; she had digestive problems; um, the, then there was a slight tremor in her hand every now and then, but it wasn’t all the time. I think that’s what I noticed first. And the, the tremor started, and then I’d look down at her hand and she’d grabbed that hand with the other hand as if, you know, to stop it from happening. But she clearly didn’t have control over it. And um, I can remember it must have been the fourth appointment.

I mean, poor mum, had a camera down her throat; she had a camera up the other end to check her digestion. Um the terrible back problems she was getting. And every time you saw the GP, they were tackling each thing, you know. ‘oh, you’ve got a bad back, we’ll deal with the bad back’; ‘oh, um, you’re having problems with digestion’, you know, ‘we’ll deal with that’; send her for tests. I can remember, I’m sure, there’s about four specific things (with the GP), with the GP. And the GP would refer to the Hospital to get it checked, and I remember what the last time, just before she got diagnosed. I went to the Doctor, with her, again, cos I always go, cos as I say she’s not very good at articulating things, and, um, I got frustrated. And I said, ‘why can’t you join the dots, clearly there’s something wrong; there’s something more wrong. And I don’t know what, cos I didn’t have clue’.

You know I had heard of Parkinson’s, but, you know, I didn’t know what it was. But nobody seemed to be looking at the previous record of, you know, the fact she was coming back like practically every month, or even a few weeks apart with a slightly different problem. And this was out of character, mum never used to go to the, she has had hypertension, you know, since I can remember when I was a child. And she took tablets for that.

But, um, that was one of the other things, her blood pressure suddenly fell through the floor. from having hypertension, she had the opposite problem, so it, having all these things add up to something being wrong. And of course, you’ve got good old Google, and I was googling. It could be cancer; it could be Parkinson’s, you know, so we didn’t know. There were three things, potentially, that it could be that could cause all these symptoms, but as I say I got to the Doctor and said this and next thing they, um, referred her to Neurology. And she had a Brain Scan. And it was when she had the Brain Scan, as I say it took a good 18 months, finally they could put a label on it, and say actually all of these things are connected. And you don’t know you’ve got it. I guess the tremor was the biggest giveaway.

**Interviewer:**

**And was that 18 months from when she first saw the Neurologist or when the symptoms started?**

**Answer:**

No, when the symptoms started, yeah. Cos we were going, and we were being treated, sorry she was being treated for different things, each thing. So, I do, you know, I do wonder, um, how GPs, it’s not easy to recognise it. I suppose bit like Pancreatic Cancer, that you know my mother-in-law had, and that’s not easy to recognise. But this is harder to recognise until you actually start really getting tremors, you know, then it’s more of a possibility. But, um, yeah, I was very worried about her; certainly, horrible to had to go to, some of the tests she had were horrible. I wouldn’t want them myself.

**Interviewer:**

**And you were saying that, um, someone gave you information about Parkinson’s after that**

**Answer:**

Yeah they did. They gave us a little, um, I don’t know, a tiny, very narrow but it was like a foldout leaflet and I think it was an NHS, and it was, um, something with Parkinson’s. it could have been Living with Parkinson’s or, so now you’ve been diagnosed, and this is what it is, history you know.. so yes she had that leaflet but, um, me being me, I spent time on the internet thinking, ‘oh gosh, you know, what’s going to happen next; how quickly will it progress’. I suppose that’s been my biggest thing all the way along, thinking, ‘crikey my mum will end up in a wheelchair’, all the time, at some stage I accept that.

But is there anything out there; is there any research studies, you know, and I know certainly, even with (PD specialist), I have been questioning the tablets which is Stalevo, that he put mum on. Cos mum used to be on, um, Sinemet and Entacapone separate before we arrived in this area, and suddenly it’s combined pill. But she never used to have Dyskinesia. And as soon as she got on that combined pill, she’s got Dyskinesia so, I understand, um, enough that Sinemet is the active thing that helps with the Dopamine in the brain. And the Entacapone, um, makes the effects of the Sinemet last longer, and I know that much.

And mum was okay on that, for years and years and, well it felt like years (giggle). I don’t know how long actually, you know, just on those, trumming along. Um, but then gradually her clockwork battery, if you like, her Duracell battery run out and it was like her feet sticking to the floor, it was when she was living with me. You know, she was going between the furniture, and she would hold on to the furniture as she went but, she would like suddenly slow down and say, ‘oh, I’ve got to sit down; I need to rest’, you know. And, um, that was when we decided, ‘oh we needed to get her sorted here’. And then the, the drugs were changed and um, as I say, I did question (PD specialist), but he just said, ‘that’s the best thing for her’. So,

**Interviewer:**

**And in terms of, you know, learning, so you said Google, and you clearly know a little bit about the drugs, quite a lot about the drugs. Um, how was it looking up information online – was it easy or difficult to understand? You**

**Answer:**

It’s, oh, to begin with it’s hard because you get a term, and you think, ‘heck I don’t know what that means’, so you’ve got to look up the term, you know, and then string the sentence together. But, actually I have to say, one of the best things. We had a Parkinson’s Nurse come here, and she was explaining about the drugs and um, she said, ‘oh, it’s a shame you’re put on the Stalevo because we can’t adjust the dose of the Entacapone to the Sinemet. You’ve got more control if they’re separate’. And I remember her saying that, and it logged in my brain somewhere that that was of interest because, as I say, when the Dyskinesia started that course brings you all sorts of other problems. The muscles are going cuckoo, you know.

So, um, that, that was a worrying side effect of the tablets, and I must admit I have questioned (PD specialist) about it on more than one occasion. But because of covid, the, the time, the first time we met you, it was the first time we had met (PD specialist) as well. so, it’s very difficult to have a telephone consultation when the Consultant can’t see the patient because, you know, you’re describing it, but my mum couldn’t describe her symptoms so well. Um, but, and yes, I’d never heard of the word Dyskinesia before, you know, now I can say it flows off the tongue. But to begin with, um, yeah, it was hard, and I had to look it up. And I’ve learned a lot, but I did learn a lot as I say from the Parkinson’s Nurse, she was brilliant.

**Interviewer:**

**And, you know, the online search was that did you find useful things, you know, Google can bring up quite a lot of things about Parkinson’s**

**Answer:**

Yeah, you’re right. And it’s a case of trying to sieve the wheat from the chaff, also not get panicked about it, because you can, you know. Like you, as a Doctor, you research things on Google and um, you know, mums experienced it, um, but different Doctors find different things. So, I was getting stuff from America; I was getting stuff from the UK. I tended to stick to the UK because, I don’t know, it’s just my country and I feel better about it. Um, but, um, something MD, it was an American site that I found useful, but I honestly couldn’t tell what it. If I looked it up now, I’d find it, but it was something MD and I, I did use that quite a lot as well. But then, although I’ve learned things myself, I’ve not passed them onto mum, because it would over complicate her life, you know.

Mum just needs to work on the day-to-day, and what she can do today and what she can’t do today. We just, yesterday actually, had the results of her heart scan. You don’t want to hear this, but the heart scan said that she’s got an enlarged aortic something or other, but it’s caused through hypertension. And mum, mum said what does that mean, and it, basically, it’s the systolic functions okay and everything else was okay. But the bottom line was, ‘oh, no actions, for her age she’s okay’. But I read that, and I read a bit more, and I thought, ‘oh my goodness’, you know. There is a bit more to it, but I would never tell her, yeah. It’s so, I’d rather she just carry on in her own way and think everything’s hunky dorey.

**Interviewer:**

**Yeah, yeah, of course. And um, you know, you said something she’s got hypertension. Does she have any other medical conditions other than her Parkinson’s, you know, or she’s had?**

**Answer:**

Oh no, she had hypertension from, aw, crumbs, she must, well at least her 40s. Um, all through her life, and it wasn’t until, aw, crumbs, when did dad pass, I don’t know, it must have been 2019. Suddenly her blood pressure dropped, and she was taken off the pink pills as I call them, the hyper, the stuff for hypertension. Um, but that was her only thing. Oh, she did have repeated Urinary Tract Infections, so every so often she’d go and have to have Antibiotics for that. Um, and then I learnt that she was allergic to a, an antibiotic, um, I can’t remember its, Macrolide, anyway there’s a family name for the thing. But, um, you know, you just learn as you go. Um, no, that was literally it, high blood pressure only, and occasional Urinary Tract Infections. But they were common, you know. I remember growing up; mum had these things, so, that was normal, yeah.

**Interviewer:**

**And you talked a bit about the medications, do you know how many medications she takes in the day?**

**Answer:**

Oh, 11 tablets a day.

**Interviewer:**

**And how many different times a day is she taking them?**

**Answer:**

8 o’clock; 11 o’clock; 2 o’clock; 5 o’clock; 8 o’clock and the patch all the time.

**Interviewer:**

**So … you use Alexa. How did you come up with thinking about using Alexa as a reminder?**

**Answer:**

Um, we got it for my dad actually, originally, so that he, cos he had, um, heart, Congenital Heart problem, and so he literally could hardly leave his chair towards the end, and he was on oxygen. And we got the Alexa, or my daughter bought it for him I hadn’t even heard of it before. She turned up with it, and it meant that, um, my dad had a very active mind, but it meant that he could ask her for things, you know, ask Alexa for things, and play music. So, you know, the old Nat King Cole, which drove me crazy but, you know, that sort of thing. And then, um, I, they were doing that, and dad was asking her questions and mostly it was like. Dad liked to play games with her, you know, ‘beam me up Scotty’ and all this kind of thing, you know. Dad’s sense of humour. But then, um, I thought, ‘aw, I wouldn’t mind one of these’.

So, I got one myself, and when I got the leaflet and started looking at it, I thought, ‘oh crikey, I can use it for timers for my cooking’. Um, and it was my daughter that suggested setting the reminders for, um, you know. And she’s in her twenties, yeah, for mum and dad for their medication. And um, I thought great. And of course, mum then came here; we upgraded to the show, you know the one with the screen which means we can have video calls. And my two daughters, both in their sort of like mid-twenties, they can video call my mum and see her. And that’s kind of reassuring, so, um, yeah, oh my goodness that’s probably been the biggest aid to mum, you know, not forgetting. Cos let’s face it ninety percent of her time is home in her little bungalow, you know. The occasional visit, and um, like, I think her shopping arrives today. She does online shopping believe or not, my mum, she’s quite good with the old Tesco shopping so she can do that. it takes her hours to do, to get one order, but she does it, and I get stuff in-between for her. But you know

**Interviewer:**

**So, the Alexa helps with the timings of the medication**

**Answer:**

Oh gosh yeah.

**Interviewer:**

**And you said, um, she puts out the pills herself?**

**Answer:**

Yes she does, yeah. I’ve helped her it, on occasion and when she had to go into hospital a couple of times, I’ve had to quickly, you know, a bit quicker than she is at getting them, but um, putting them in the compartments for her. But, no, mum takes her time; she does it one pot at a time, systematically. Well, she’ll probably show you when you see her, but she’ll open the, well she can’t open the pot they’re too hard, that’s another thing that all students should note. You know these child locks, she can’t physically do it, and when you’ve got Parkinson’s it’s near on impossible, so I have to open the lids for her. And hope to God she doesn’t know them over in the process, but, um, I loosen the lids so she can then get them open. And then she’ll, um, put them in the pot at the start of the day. And then she’s set up for the rest of the day.

**Interviewer:**

**And how about prescriptions or getting medications?**

**Answer:**

Um, previously I’d gone up to get them for her. And there was one occasion when I couldn’t get to the Pharmacy, and I, and mum was desperate for the medication cos it had been changed, the dosage had changed on something, and mum likes to follow what’s on the pieces of paper, you know. If the prescription says this, I will follow this, you know. And what (PD specialist) doesn’t know, is that mum had only been on the lower dose of the Stalevo for two days because it was written down on the prescription. He’d already told her previously to take 100 milligrams of Stalevo for the first two doses, the 8 o’clock and the 11 o’clock, and she’d been doing that.

And then mum decided on her own, um, to follow what the piece of paper told her to do. So, she went the first dose is 100 and then the second dose is 75, but that was literally for 2 days before the Consultation. And she’s too embarrassed to mention it. So, of course (PD specialist) put her on the increased dose so to be honest it’s not really going to make a lot of difference, you know. Um, 25 milligrams or micrograms, whatever it is, the MG isn’t it.

**Interviewer:**

**So, the instructions and the paper had come from**

**Answer:**

Oh, the prescription? That’s her instructions yes, prescriptions. It says take this at these times, you know, she needs that. she definitely needs that. if it’s written down she’ll follow, and, um, she’s not very good at deviating. And when (PD specialist) said, ‘take the 100 milligrams twice a day,’ she did that for quite a while for, you know, he probably remembered the previous consultation when he told her, she was doing that for a long, long time. And then the prescription came through, and it only, it said, ‘75 milligrams’ instead of 100 milligrams on the piece of paper, so mum took it on herself that, you know, when the repeat prescription arrived to go to 75 milligrams. Of course, all he’s done is put her back on the 100 milligrams.

**Interviewer:**

**And where do you think the error was. Obviously, if the doctor was saying 100 and the prescription coming**

**Answer:**

Well, the prescription clearly said, 75 milligrams at 11 o’clock. Um, now that I’ve read the letter, it arrived yesterday. Cos whenever mum gets a letter, and she shares it with me, and it actually does say, 100 milligrams on the letter. I just hope that the GP Surgery will pick up that letter and read 100 milligrams and put that on her repeat prescription paperwork. If it isn’t, mum will forget, and she will go back to 75 milligrams even though she’s been told she should have 100. So, yeah, yes, thinks like that is something I keep an eye on; I’m aware of it, and check

**Interviewer:**

**So, you check the doses and prescriptions**

**Answer:**

Yes, and (PD specialist), um, previously had changed the dose, and he forgot to tell the, um, GP Surgery. No, he told the GP Surgery, he forgot to tell mum that the dose had changed. I went to collect her prescription; I looked at it and said, ‘no hang on, you’ve got the dosage wrong’, and although it was on the paperwork, this isn’t what she was on previously. And because it hadn’t been communicated, I rejected it and said, ‘no, she’s not on that dose, she’s on this dose’. And then I got the Pharmacy to check the, the prescription and then they said, ‘yes she was on this dose’, and and they said, ‘this is what’s come through’.

Um, and in hindsight, I suppose I should have gone back to the GP, I did go back to him because they’re next door to each other between the GP Surgery. But unfortunately, it wasn’t clear where the higher dose had come from. Um, and then, we spoke with (PD specialist), he said, oh, he understood why I’d rejected, because I’m not going to let mum suddenly take a higher dose of something because I’d worry, um, what effect it could have. So, he said, ‘its alright they’re going to copy us in any letters between the GP Surgery and himself.’ It’s okay, I’ve got no problem with him changing the medication just keep us in the loop, because I’m watching (giggle).

**Interviewer:**

**Yeah. And obviously with that, that issue, did you go back to (PD specialist) to clarify?**

**Answer:**

Yes. And he then put that in writing and said, you know, he wrote a nice letter and it said he would, include us and the letter came to us as well in future correspondence. And I’m glad to say that’s what’s happening now, thank goodness.

**Interviewer:**

**So, that’s very useful having it**

**Answer:**

Oh yeah, yeah.

**Interviewer:**

**And how do you think, you know, your experiences with healthcare communication has been between the Hospitals and your GP and yourself and that …**

**Answer:**

Um, not great, I have to say, yeah. Um

**Interviewer:**

**In what way?**

**Answer:**

Well, the GP and the Hospital don’t, well maybe they do, but from my point of view they don’t appear to talk to each other. And, um, when you go to see the Doctor and say, ‘mums had a fall’, um, it seems to be a surprise, you know, when you talk to them. Um, so, um, it’s a worry, yeah it’s a worry. But, but then of course they’ve got how many people to deal with, so I get it, you know. I’m only interested in my mum, but how many (name) are there interested in their mums?

But, having said that, they, since mum did have her fall; she got referred to the Falls Clinic. And I’m not sure if that was, where that came, whether it was from the Parkinson’s Department at the Hospital or whether it was the GP referring. So, I don’t know where that originated, I was just thankful that it did, because it turned out that mum was using her wheeler all wrong, and things like that. And it would have done damage to her back long term, cos she tries to pick it up off the ground. You know, simple little techniques that she needs to understand and me, for that matter. So, I sat in on her sessions because mum, unfortunately, is forgetting things now, so I can remind her, yes. I say remind, I feel my role at the moment, is to be constant nag and tell her, ‘you need to do this; you need to do that’. ‘oh yes’. ‘Remember so and so told you this’, ‘oh yeah’. She doesn’t remember at all, but you know, you live in hope (giggle)

**Interviewer:**

**And, um, how has her appointments been, or has she seen the GP for any problems with her Parkinson’s**

**Answer:**

Oh, you’re joking. Has she had a face-to-face thing? I don’t think she’s ever met her own GP. Yeah, admittedly she only moved in February, and we’re now in August, yeah. But err, um, yeah, no I don’t think she’s met

**Interviewer:**

**And do you think that’s because of covid or?**

**Answer:**

Yeah, yeah. I’ve, um, spoke. We met, um, a Locum when, err, um, when mum had blood pressure issue and they were saying, ‘oh, we need to keep an eye on her blood pressure’, and they were saying she needs to take readings. And mum can’t physically put the cuff on herself, and I just said, ‘if you want mum to have readings, then you need to put one of these 24-hour monitors on, and just leave it on and let it do it’s thing.

And that is the only way you’re going to get a true reflection of what her blood pressure’s doing because I’m not living with her now so I can’t physically’, well I could I suppose run up, couple of miles down the road and put it on and take it off. But nobody in their right minds is going to be doing that, so we got one of those 24-hour monitors. And, um, we thought, great and that was from the Locum that had suggested that. that was good, and it took a long time to arrange, because there’s a limit to how many they had at the Surgery, of course, fine. Um, so when mum did get it that was fine.

But then we didn’t get anything, any feedback to say it’s okay, or it’s not okay, or nothing. It was like a big black hole. Oh, well, all of my attitude is well, ‘mum don’t worry about it because if there was a problem they’d be in touch’. The same with the heart thing, how many weeks ago did she have the Heart Scan? You know, um, when we didn’t hear anything, from anyone. Um I said, ‘well if there was a problem, they would have been in touch’. And that’s the way I treat, well I hope to goodness that’s the case. But the letter, as I say, came through but I don’t know when the actual, I can’t remember when the actual appointment was, sometime ago.

**Interviewer:**

**A bit of a delay sometimes**

**Answer:**

There is a delay, but, you know, we can live with that, yeah.

**Interviewer:**

**And how was the telephone appointments compared with the, you know. Has there been any difference?**

**Answer:**

Oh gosh, yes. Well, if, a telephone appointment, as I say, I, I’m sure as a GP, your Doctor, observation is a huge part of your job. If you haven’t got that observation, and certainly in the case of Parkinson’s, how do you know what is really going on? You know, somebody saying they’ve got, um, a problem with the shaking or whatever. My mum, if she was trying to explain it on her own she says, ‘I’m a bit wobbly’. That doesn’t mean a thing, does it? ‘Or I’m feeling weak’, it doesn’t mean a thing. Um, and the example, ‘I ache all over’, that doesn’t mean. and cos I’m closer to mum, I can probe her and say, you know, ‘you ache all over, what does that mean’, you know. Cos its too general, you know. You ache means you’re hurting, you’re in pain. Well, where are you in pain? Is it your arms; is it your legs; is it your neck; is it your head, you know. You can do this and try and get to the heart of the matter and unfortunately sometimes it’s like trying to get blood out of a stone getting the information from an elderly person, my mum. Um, but equally I think the appointments, over the phone, to be honest I don’t see. Unless I’m there to talk her corner, which fortunately I was when we had the conversations

**Interviewer:**

**You put the phone on speaker and be…**

**Answer:**

Yes, that’s exactly what I did. Um, and every now and then if mum had said something, and she’s a bit vague, I’d say, ‘well actually it’s a bit more than that’, but you know you have to be quite assertive sometimes. Um, cos, mum, she can’t help it, it’s her age; its um, what is it, they call it white coat syndrome. Do her blood pressure when she’s at the hospital, her blood pressure will be up, higher, um, but it’s the same when she’s talking to someone she gets herself in a bit of a tizzy. And it’s good that you’re going to see her in her own home, so hopefully she’ll be more relaxed when you do get to speak to her.

But um when she’s with an official it’s completely different. As I say, remotely, um, over the phone, in my opinion it doesn’t really work. And, um, you come away more frustrated when they say, ‘oh, up this by 25 milligrams; or we’ll give you another dose of this in the day’. Um, for me, that’s not sufficient, but for mum its like, ‘oh, I’ve got a pill, it’s going to be okay’, But that’s, you know, yeah, the placebo effect or whatever, I don’t know but I need to know a bit more; I need to know what the pill’s doing; why its increased; will it make a difference. I don’t really see that the 25-milligram difference, um, is going to make any change, any difference to mum whatsoever, in my opinion. But mum thinks it might, so that’s fine. And if she feels happier about it for a while, but to be honest, it won’t be long before she’ll be needing help again, sorry.

**Interviewer:**

**You say you always go to all the appointments. From your point of view, how, what has your experience been with, you know, Parkinson’s appointments**

**Answer:**

Actually, being here, um, its, it’s been very positive. As I say the remote thing, it’s a, it’s a problem but I understand because of covid. And the same with the GP. You try and get an appointment with a GP. As I’ve said she’s never met her GP; she’s met one Locum, once with a physical appointment.

And I’m sure that information isn’t actual, maybe it is, isn’t recorded to say, well when the persons had an appointment did you actually see them? Or was it just speaking to them on the telephone. And I think that information should be recorded because if it goes on and on and on, yes it’s all very convenient for the Doctor to be sitting in their armchair, or wherever they are, in their office or wherever, making phone call after phone call and reassuring people. And say, ‘take your Aspirin’, or whatever they need to take, um, but I’m sure it’s very convenient for the GP and they can get through a lot of people.

But the person on the other end, it could be over a year before they actually see a Doctor. In the meantime, something bad has happened, you know. I’ve got a friend who’s now going to have their toe amputated because of gangrene, that’s up in Cambridgeshire, you know. A completely different subject but that’s an example of what covid and GPs, you know, they’re begging to see the GP and the GP’s saying no. Or maybe it’s not the GP maybe it’s the Reception Staff or whatever that’s, you know, whatever their instruction is. GPs and patients are not seeing face-to-face, and that doesn’t work.

**Interviewer:**

**And have you to be in touch with anyone if you’ve had a concern or question about mum’s Parkinson’s have you**

**Answer:**

Oh, yes, yeah

**Interviewer:**

**And who did you go to?**

**Answer:**

Um, actually the Parkinson’s Nurses, yeah

**Interviewer:**

**And how was that experience**

**Answer:**

They’re, they’re really good. They, um. They’re very hard to get hold of, but you leave a telephone message, and they will phone you back.

**Interviewer:**

**So, you’ve got a number to …**

**Answer:**

Yes, and that is brilliant. And the other thing we’re planning to do, which mum’s not so sure about, is um, go to the Support Group. Apparently there’s a Support Group, you might be interested for your research I don’t know.

**Interviewer:**

**Parkinson’s UK group is it?**

**Answer:**

Yes. I said I think it’s worthwhile because, um, I’m concerned about the medication mum’s on. I’d be interested to learn, um, no offence to any Doctors or anything, but I’d be interested to learn. Is everyone in this area; are they all on the same drug; the same dose. Be interested to see different people at different stages, because I know this is progressive. And, um, is there something that somebody else’s doing, or has, that improves their life significantly. Um, rather than someone, like my mother, who puts up and shuts up and just gets on with it, you know, and spends day, or two days, you know. Gets up and sits in the chair and can’t even do her laundry or, um, things like that. She’s

**Interviewer:**

**How did you find out about the Support Groups?**

**Answer:**

Um, I have a friend here. She’s got a friend with Parkinson’s and, um, it was her that put us onto the Nurses originally, cos, it was, mum wasn’t given the number to begin with.

**Interviewer:**

**Oh yes, oh right. Of the Parkinson’s Nurse**

**Answer:**

That’s right. (oh, right so) so we had, because I’m Hampshire, and mum is Dorset and we’re on the border, when I tried to get mum referred when she was living with me, was near on impossible. And, um, they rejected her, I think it was Poole Hospital had rejected mum, they said ‘oh no’. And

**Interviewer:**

**Because her address was here.**

**Answer:**

Because her address was here, and that’s a whole another issue. And I can’t remember how long it took, but it took some months before I can find someone who, would, what we thought was a Parkinson’s Specialist to actually take mum on. And that was a big worry because I thought, oh, you know, mum’s come to live in this area and um, she can’t even get to see someone who knows about her condition. And obviously you wouldn’t expect a General Practitioner to know everything there is to know about it.

**Interviewer:**

**Did the GP make the referral or?**

**Answer:**

Um, yes. Initially, it was the GP made the referral. But as I say, um, when mum was registered at (GP practice), because although we knew she was going to be moving to (town), they said. Um, we said, ‘oh it’s going through; the house sale is going through’. ‘Oh, she doesn’t actually live there yet, we don’t cover (town) you can’t sign on’. So, they said you’ve got to sign on with the (town) GP, which we did, but um, then they say, ‘well we’ll refer you to Parkinson’s people, Consultant, but then by the time mum had moved it was all a waste of time anyway. But she’d been rejected, I think by two Doctors originally, (city) Hospital and somewhere else before mum finally got, um, the, you know

**Interviewer:**

**That must have been quite stressful, quite**

**Answer:**

Oh yes, it’s, yeah. its quite normal for things to be stressful (giggle) where that’s concerned. I just think, um, I’m one of these people, how do you eat an elephant, one bite at a time, you know. You’ve got this mountain to climb; the only way to get to the top, just keep, keep going. And I’m quite tenacious, I will keep going till I get a satisfactory answer. Mum couldn’t carry on without having anyone that, um, you know, knew about the condition or more about the condition. Or it was up to me to find out, which was partly why I started researching the condition; learn what I could about the drugs and things, um, you know. Amazed I saw on the internet like CBD and things like that to stop it. I asked the GP about it, and they said, ‘oh no, that’s a nonsense’. And yet the videos and the effect is clear to see.

And then there was another drug on trial, wish I could remember the name of it, I’m remembering too many drugs at the moment. But um, and that seemed to do a lot of good for people, but then they stopped the trial in it’s tracks because of somethings’ questionable. It just takes one person to have an adverse reaction and it stops things, which you get, but you know, you hope somebody’s going to pick up the reins and carry on to get it, you know, you just want this miracle cure. And you know its not really going to happen but, oh boy do I wish mum’s life would be easier, you know.

**Interviewer:**

**And I suppose thinking about, you know you talked about medication, appointments, seeing GPs. Is there anything else that you do to help with mum’s health? So**

**Answer:**

With her health? Um, no, I mean, I will comment if she’s. Cos mum used to take great pride in her appearance; she used to roll her hair up every day and things like that. and while she was here she was okay, and she was doing it, but since she’s been living in the bungalow on her own, um, she could go quite a few days not bothering. And I’ve pointed that out to her, um, and she started rolling her hair up again, you know, making an effort, but I don’t want her to give up. I don’t want her to, you know, curl up and die basically. And be a forgotten person.

Um, I would love to be able to do lots of things with my mum, you know. We were planning holidays; we, neither of us have ever been on a cruise, and we said we’d love to go on a cruise but covid’s happened so that’s not gonna happen now. Um, and we equally won’t get on an aeroplane because of the risks are too great, so we’ve got to make the most of what’s around us. And luckily we live where we do.

But one example is, like she’s not seen the (city) Fireworks, I know it’s only a silly little thing. And I had my daughter come last week and we went to see the Fireworks, which was lovely, but then because we weren’t sure about parking and getting mum close enough and all of that, she said you’d better go on your own. And I feel she’s missing out. And you know, you know you can’t push the wheelchair up a really steep hill or whatever, if I’ve got her in the wheelchair but, now I know where I can park I’ve said that next time I’m taking her with, and things like that.

But, um, it changed drastically but, I’m trying to find things she can look forward to, you know. Old people, they go, they quite often go into homes and they seem to get forgotten. I don’t want that to happen for mum. I’m quite, quite keen for her to be as active as she can and that’s why I, I go round so regularly to make sure she’s done her hair. Mum can’t do up a zip on the back, she won’t admit that either. If she’s wearing a dress her zip will be like a foot down, cos she can’t actually do up her zip on her dress anymore.

Um, I’m talking now, broached the subject about Carers, and moving forward. Um, washing sometimes, I have to remind her things. She does really well, um, and she’s she’s kind of coping, but some days she just feels so horrible she doesn’t, she just doesn’t want to, um, and I’m constantly nagging and pushing, but

**Interviewer:**

**How is it, you know, you talked about Carers. How was it finding information about if you needed them where would you go to?**

**Answer:**

I did it for my father so, um, yeah, mum’s seen it, and been through it with dad because saying it’s not fair that she’s got Parkinson’s that she can’t care for my dad as well, um, as trying to sort her own problems out. And so, we set it up for dad. Um, there’s Age UK; there’s, you know, that’s how I got mum’s cleaner in Surrey from um, but we’ve got a cleaner here that I’ve organised for her. She’s sorted out her own gardener through speaking to the neighbours which amazed me.

Um, wow, um, but um, more times I, um, am the ones making the calls. So, if it’s something that she, she’s not comfortable with making phone calls to strangers. And, you know, I do bills for her and things like that so, I do. I do the practical stuff, you know.

Um, but personal hygiene and um, things like that, I, I could be a Carer I guess, but I said I thought that would change our relationship and I want mum to be mum, and us to have enjoyable things together. (of course, yes) So, yes, I don’t want to change the relationship. So that’s why I think it makes more sense, and I said the same for mum, you know, with dad, it’s better to have somebody from outside come in. I think you have to be in the right space mentally to actually accept, ‘actually I’m not coping any more’ and it takes a lot to admit that.

And I think we’re, we’re just, we’re having a conversation every so often, and I bring it up if I spot something’s not, in my opinion, not quite right. Um, then at least I can talk about it, and mum says sometimes, you know, when I said she forgets, she’s exhibiting signs of Dementia, mum was horrified at that when I started listing all the things. And I said, ‘well, actually it’s nothing I haven’t pointed out. You did put stuff in the wrong cupboard; you did forget to put the cheese in the fridge; you did forg, you know. Its’ no lies, it’s truth. But when it’s happening, individually, mum doesn’t realise just how bad it is, you know, what she’s getting.

And I think that was a bit of a wakeup call and, I think, on the phone, um, she was speaking to someone and I was in the other room, I could hear her speaking cos she has it on speakerphone anyway. And err, and she says, ‘oh yes, and (daughter) reckons I’m losing my marbles’, you know, derr. No, you’re not losing your marbles, but yes you are exhibiting signs you know, it’s a difference where we’re not totally there yet; we’re not having repetitive conversations on the same subject like other friends whose parents have gone that way. Not at that stage yet, hopefully it won’t happen touch wood, you know, but um

**Interviewer:**

**It the perception**

**Answer:**

Yes, that’s right. And things. And she says, ‘I know you’re saying things for my own good; I know you wouldn’t say anything to hurt me, you’re doing it for my benefit’, but she says, ‘it is hard to take’. (giggle)

**Interviewer:**

**Of course. And from your point do you feel overstretched with what you do to help, you know, your mums Parkinson’s**

**Answer:**

If I had a full-time job, um, I would be in big trouble, yeah, I wouldn’t cope. Um, but, since I moved here, in 2017, um, fortunately I was, I sold my property. I brought two properties; I’m able to live off the rental although it’s not a luxury life, when I’m, you know, doing a lot of stuff myself that I wouldn’t, that I’d love to get people in to do things, um, I manage. But it’s freed me up, which means I can spend more time being there to care for mum, you know. I’m a phone call away. And again, we’ve got the Alexa thing set up, and she’s just got to shout Alexa, ‘call (daughter)’, and she’ll get through to me, you know. So, um

**Interviewer:**

**How far does mum live from here?**

**Answer:**

It’s only (town). It’s only a couple of miles, its not far. Oh, well, there’s the cycle path, that’s really, that’s a couple of miles there. It takes longer by car, but it’s a 10-minute drive, so it’s okay I can be there very quickly.

**Interviewer:**

**And do you think this has had an impact on your life and social networks**

**Answer:**

Oh, yeah. what social life. Yes, um, I went to a wedding, friend’s wedding, recently and I met a very nice man who lives in the Cotswolds. And I, um, went to the Cotswolds, I had one night away but I wouldn’t consider going away for any length of time because I know it wouldn’t be right. Yeah, what social life. Gosh, um, yeah. My social life is more with mum, and more with family so I’ve just changed it. Yeah, and people, I have friends come to me, but they know that my priority is to make sure my mum’s okay.

And actually, I’ve got a girlfriend, um, I used to work with years ago, coming today. She wants to see the Fireworks in (city) this time. So, um, yeah, I’ll be doing that for the evening, but I will be contactable all the time to my mum. I tell her where I’m going, so she tries really hard, and she’s very good.

Um, but yes, if, if I had a full-time job, that’s why I’ve only worked part-time since I’ve been here, um, and, if I didn’t have, you know, if I was less fortunate and I didn’t have another property that I could get an income from, um, I don’t know what I’d do. It’s like, I think mum would just deteriorate very quickly; I can take her to the shops, you know, silly things. You know, silly things, she might need a pair of tights or, or, you know, something very simple, um, but your necessities. Um, she’s moved into an area; she doesn’t know the neighbours, you know, and making friends at her age is a lot different to making friends at a younger age.

I, fortunately, my personality is that I make friends very easily, and I, I have a habit of trying to get people together that, you know I think, ‘aw, they’ll get on’, or whatever. So, I introduce other people to the people I might have just met, even though I’ve only met them like a week before. But, um, I think it’s a good thing. I think the networking and the talking, and that’s why I’m thinking about the Parkinson’s Group which they put off because of covid but I believe it’s starting again. I think, this week actually, I think it’s due to start, so that’s what’s I would like it to keep it all involved, yeah.

**Interviewer:**

**I suppose what other, what things have helped you manage with medication, the appointments and mum with Parkinson’s, what, do you think it’s something else that helps you cope?**

**Answer:**

Helps me cope. Well, I, my mental state at times is a bit frayed, or, you know, occasionally. Luckily, I’m the sort of level-headed person so I can cope. Um, every now and then I want to let off steam; I find it really frustrating, I’m sure my mum finds things frustrating, but I do find it frustrating. But it’s just having mates at the end of the day, someone to talk to. And, yeah, if you’ve got a friend that you can talk to but um, yeah, but nothing physical that. Al the physical things that I think can be done, I am doing but I don’t know of anything else so, unless you’ve got suggestions. And you think, ‘oh, you know, this’ll help you’. But no, coping, you know, yes non-existent social life but then, you know, you’ve got to, haven’t you, you know.

**Interviewer:**

**I suppose, yourself, do you have any medical conditions yourself?**

**Answer:**

No, thank goodness. No, apart from when I pulled my shoulder from the wheelchair, but apart form that, no. I’m always at the wheelbarrow why not run. (giggle) No, I don’t, nothing. I take no medication.

**Interviewer:**

**And from your experience of healthcare systems and healthcare professionals, do you think there are ways that the healthcare system can be improved to help you manage mum’s health with Parkinson’s? From your experiences**

**Answer:**

Actually, what healthcare really it’s just about being joined up. It’s all the different departments. I think the biggest frustration is the different departments not talking to each other, you know. First was getting the diagnosis, which as I say probably took 18 months. Um, but then how could they diagnose something they’ve not come across, you know. They. GPs are so pushed at the moment, you know, they’re expected to know a plethora of information about all these conditions and how are they even got time, you know, because they get such a short time. What is it? A ten-minute slot. I think, I don’t know what the time is, but I think it’s roughly 10 minutes. They get 10-minute slot with someone; what’s the problem and that’s it. And then they won’t see that person for ages, you know, they’ll go away.

And from what I’ve observed, with the old people, they do go away and be quiet about something you know. It’s like when you’ve got a problem, you’ve got to keep on; you’ve got to, you’ve got to keep saying it, so yeah, that’s the only thing I can think of you know. The different departments joined up.

I guess now, you know, on TV they talk about mental health, um, the, um, different departments, you know, the Police that are now getting joined up with people. And they’ve got Mental Health Specialists and stuff like that. Um, but that means sharing people’s personal records with all these departments and a lot of people are private and don’t want that. its, where do, honestly I haven’t got a magical thing, I can’t say, but I would like the different things to be joined up a bit, just a bit, you know.

Um, but I can’t fault, as I say, the Pharmacy when I couldn’t get mum’s medication, and I phoned them, and I said I really can’t get there. And it’s, literally the end of mum’s road, you’ll see where it is. I could walk it in 2 minutes, or running 2 minutes, um, it would take mum quite considerably longer. Probably take her half an hour to get there. But, um, when I called and said she’s not in a condition to walk, can you get the medication to her, you know, cos I was out of ideas. And they said, ‘oh yes’, and they did it that time. And then when she had her repeat prescription, they brought it to her, and she hadn’t even asked. They just turned up with her medication, and she was like, ‘oh, that lady from the Pharmacy came round’. And I thought, wow, you know, that’s what it should be shouldn’t it? That’s what community, and you know, people, you know.

The Pharmacy and the GP I would say there’s a problem between the two, because if the Pharmacy have got something and it’s not right, they say you’ve got to go back to the GP. And then, fortunately, they happen to be in (town), they’re next to each other. But I’ve, I’ve probably taken 20 minutes running between the Pharmacy and the GP, where the GP said something, well via the Receptionist, cos you can never see the GP. And then you go back to the Pharmacy, and they say ‘right, right medication, right prescription should have come through now’, cos they’ve sent the wrong prescription for whatever reason. And um, you get to the Pharmacy and they say, ‘it’s not come through, it must be in the ether somewhere’. Well, how useful is that? think, right, okay, well can we e-mail it?

Is there another method, because I’m sure this automated whatever, so I’m like trying to get, you know, practical solutions? I haven’t been given a piece of paper, it gets sent electronically sent, and it hasn’t arrived. We’ll give it time, so we’ll sit in the car for 10 minutes, And I’m thinking, ‘do I take mum home; how long till the next tablets’, and you know all those sorts of things. Um, and then you sit in the car and you think, ‘okay, has it arrived’. So, you go back into the Pharmacy having sat in the car. ‘Has it arrived yet?’ ‘no, it could be in this queue’, ‘or it could be in that queue’. Like what queues, you know, the virtual, you know electronic queues wherever they are. ‘No, definitely haven’t got it’. Okay. Go back to the GP, and I’ve actually done that. Backwards and forwards between the Pharmacy and the GP until I actually, finally, the right bit of paper was sent electronically to that one.

But in the meantime, I got the, um, I can’t remember what it was, but something. I got Pharmacy to write down the code or something, and I had to go into the GP next door because their phones were permanently engaged. You know, the Pharmacy can’t get through to the GP and the GP can’t get through to the Pharmacy. And somebody, you know, they haven’t got a runner between the two, but that’s what they need.

You know, honestly, that’s happened, I don’t know, I’ve lost track of how many times that’s happened. Where something’s been missing; it’s on the prescription but it’s not arrived. Or something’s missing off there. Saying she put a repeat prescription in for X, Y, Z, and we’ve only got X. Where’s Y and Z gone you know? Um, so they’re the silly, silly little things that I, I’ve experienced and thank goodness I’m there.

Cos mum, well she walks, takes her as I say takes her a long time to get there. And she’ll walk and she’ll go, but mum can manage that once in a day. And when she goes to the Pharmacy, and they say, ‘oh, um, go away’, well they don’t say ‘go away’. ‘We haven’t got it, come back later’. ‘Come back this afternoon’. And you know she can’t actually get back, but she needs this stuff, you know. So, she’ll contact me when things get really bad, and they haven’t arrived on time, because the, the medications she’s on, she needs them every day at certain times and if you’re missing one then, you know, you think, eek, depending on what it is.

**Interviewer:**

**Do you notice a difference if she’s missed a medication or if she’s ever missed it?**

**Answer:**

Actually, to my knowledge she hasn’t. I think she’s taken the wrong dose before, but I don’t think she’s actually missed a medication, yeah. No, she, she’s very regimented; that hasn’t happened yet. And thank goodness. Um, she’s taken things late when we’ve been out for the day and we haven’t got the Alexa on. And we said, ‘hang on a minute, you should have had this half an hour ago’. And she, ‘oh yes’, but because she’s sat in the car with me she’s okay.

We’d only notice if, um, like, you know, family birthday or something and we’re in a Restaurant, and, um, suddenly she gets up from the chair and finds she can’t actually walk to the door cos everything’s stopped. You know, and that’s just the effect of, so yes it does make a difference. Yes we have been late, um, but that’s when she’s really late taking, you know. And she’s, we’ve got involved with the meal or whatever, and she’s chatting with her brothers and sisters and forgets.

And um, then suddenly, it’s like ‘oh, we can’t actually physically get her to the car until she’s had some medication’. Of course, the Restaurant want you out so they can have the next lot in, and you’ve got a lady who’s sitting in the chair we can’t move. (giggle) so its not easy, we have our moments. Just got to remember to take the wheelchair on those days.

**Interviewer:**

**And is there anything else you’d like to add that we haven’t talked about**

**Answer:**

I don’t think so. I think we’ve covered probably everything I can think of and more knowing me, cos I talk too much