# Interview with P07\_02092021

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| * PD diagnosed in 2016 * Diabetic, hypercholesterolaemia * Daughter caregiver, Moved in with daughter during COVID * Lives alone – moved recently to be closer to daughter |

**Interviewer:**

**I’d like to start by asking some generic questions about your Parkinson’s. so, how long have you had Parkinson’s for?**

**Answer:**

Was it, 06 I think? Yes -🡪 (2016)

**Interviewer:**

**So, 2006**

**Answer:**

Yes

**Interviewer:**

**So nearly 15 years**

**Answer:**

It can’t be that long surely. 06 rings a bell with me. I didn’t think it was that long. Mind, at first it wasn’t much going on with me, and I could do it alright. What happened, the very first time, I didn’t know it was Parkinson’s or anything. I used to go in the bus into town and get off at the bus stop and walk to my house which is a 4- or 5-minute walk. And then I found I couldn’t do it. I had to stop 5 or6 times if not longer, I couldn’t walk. And so, we, we, I was having lots of tests anyway to find out what was wrong with me cos nobody seemed to know and that was for 18 months. And then I had the Brain Scan and they said it was Parkinson’s.

**Interviewer:**

**So, but you had tests for a few**

**Answer:**

For all sorts of things. Cos, I dunno, every time I went to Doctors I had something else wrong with me, which I never, I’ve always been well in myself. And I’d go out shopping and spend the whole day out; come in 4 o’clock at night.

**Interviewer:**

**Yeah, yeah. And was that your GP that you saw in the first instance?**

**Answer:**

I think it’s the Hospital one, yes it was. It was like the Doctor at the Hospital that first told me that it was that, yes.

**Interviewer:**

**That first told you it was Parkinson’s. But before that, you, it was about 18 months before and you had all the symptoms.**

**Answer:**

Well, I kept going back to me own Doctor and saying, you know, ‘I’ve got this’ and then they’d give me tests for this, and they did whatever it was, I can’t remember all the things they gave me tests for. I know it took 18 months before it was. Why I remember that cos (name’s) a very strong young lady and confident in herself and we went to the Doctor at the Hospital for the results of the scan, I think you call it a scan, don’t you a head thing. And um, the Doctor said she thought it was Parkinson’s, and (name) burst out crying. (oh dear) And I was so surprised because that’s not (name), you know. And of course, she’d thought or heard what it was before I don’t know. So, upsetting thinking that. Although she was upset in that way, it wasn’t that she was worried about the Parkinson’s, it was the thought that it took so long to find out what had caused it. At last, she said, you know what it is, what is wrong.

**Interviewer:**

**And what about yourself, how, how did that feel?**

**Answer:**

Well, I was upset for (daughter) cos she’s such a, you know, nice young lady and that, and she’s so helpful. In fact, sometimes she’s too helpful, you know. But, I felt, well just get on with it and as it comes we’ll have to face it, and what stage I get to I’ll have to come through it at that stage. And I wasn’t too, huh, worried. But as you do less you can’t do; well, I say you can’t do it; some days you can some days you can’t. And you think, ‘oh, dear, what’s going to happen next?’ sort of thing and how’s it gonna be. (yes of course) But, I accepted in some ways, but then when you go to do something and you can’t, and you think what you could do, you get very frustrated in yourself because you can’t. Like I wake up in the morning and I might feel really lovely, and I, I’ll do this or do that, and then as soon as I start to do something, I can’t walk into the kitchen sort of thing. And you think, oh,

**Interviewer:**

**That changes**

**Answer:**

That’s right. From sort of walking, 5 or 6 hours in the day, to not being able to walk.

**Interviewer:**

**Yes, of course. And thinking back when you were told you had Parkinson’s, you know, how did you get information about that?**

**Answer:**

I think the Doctor gave me some letters and forms and that to read if I wanted to. And just, she didn’t say very much, ‘it’s Parkinson’s, it’ll get worse’ or that sort of thing, not much was said. I don’t I can’t remember what she said.

**Interviewer:**

**Yeah. And since then, you know, if you wanted more information about Parkinson’s what do you do or?**

**Answer:**

Well, I’ve got the Parkinson’s things in there, cos moving there it’s awkward, you know. Where before I knew the Parkinson’s Nurses and they used to come round and suggest the tablets were changed to this and that, but of course, apart from that, getting together now but before that it wasn’t because you have to see so many different people.

**Interviewer:**

**So, who did you see as part of that?**

**Answer:**

The Nurses were, the Parkinson’s Nurses were very good. There’s one called (PD nurse specialist), she gave me her phone number and I could phone her up but not that I have. I try to get on myself, well with (daughter’s) help. (daughter) worries about me and everything.

**Interviewer:**

**And thinking about the information that you’ve been given, I know you mentioned some letters, or leaflets when you were diagnosed**

**Answer:**

That’s right

**Interviewer:**

**Was it easy or difficult to understand?**

**Answer:**

It was alright to understand but, I couldn’t believe that was happening to me cos I’ve been well all my life sort of thing. And I’ve been looking after me husband, he had heart problems.

**Interviewer:**

**Um, yes so what we were saying about, um, the information you were given and whether it was easy or difficult to try and understand**

**Answer:**

It wasn’t difficult to understand, it was just not believing it was happening to me, sort of thing. That might sound daft but

**Interviewer:**

**Yeah. and do you have any other medical conditions other than Parkinson’s?**

**Answer:**

I’m diabetic, but I’ve never had no tablets for it. So, which is good so, I keeping it alright. What else have I got wrong with me? Don’t think I’ve got anything else. (daughter) will say I have (giggle), I can’t. I’m I’m, if I’ve got anything I just dismiss it; doesn’t matter; be alright tomorrow sort of attitude. (giggle). It might be the wrong attitude, but I think otherwise you sit home crying your eyes out, (yes absolutely) and that’s not going to help you or me, or anybody.

**Interviewer:**

**And which of your health conditions, you know, including your Parkinson’s do you consider to be the main issues at the moment?**

**Answer:**

The Parkinson’s.

**Interviewer:**

**And in, what has the impact of Parkinson’s been on your, on your life and social networks?**

**Answer:**

Everything really because, I wouldn’t go out on my own now though a few months ago I would have done. But now I know I can’t do it on me own, sort of thing, and I’ve got a scooter in there. And (daughter) keeps saying that it’s my husbands’ and in the garage it is. And (daughter) keeps saying, ‘get it out and we’ll go somewhere’, but I don’t feel confident enough to be on there. Because you go up the pavements and you feel you’re at an angle and I feel I’m going to tip over, you know. And she’s, she says ‘you’ll be so much better if you could go up town’. Cos the only time, well I say town, it’s only across the road a little bit. She said, ‘it would be much better for you; you can meet people and that’. I hadn’t thought, yes it would be much better if I feel confident enough to do it.

I know it sounds silly, cos I’d go up and down, do anything before but, I don’t know, it’s hard some days. Cos you feel what is there to do and that? I like knitting; I like cooking; I like sewing and doing things, but even a lot of that I can’t do; depends what day it is or what part of the day sometimes. Cos me hands are shaking and that. Even opening a jar of something or one of those bottles took me about 3 days, I don’t know, and then (daughter) came round. A bottle, not that one, bottle, silly things (giggle). Yeah, you think, where’s it all gonna end.

**Interviewer:**

**Yeah of course, it must be a big change.**

**Answer:**

Um, that’s it.

**Interviewer:**

**And thinking about what you do, to manage your health with Parkinson’s. do you feel overstretched with what you, you do, to manage your health?**

**Answer:**

No, not overstretched at such. But I try anything but, I did go through all the exercises and that with the Nurses up there, and I done them quite well. But now, most of the time I’m too weak to do them. Like if I feel weak and I can’t doing it, when I’m feeling better I want to catch up on something I can do. Like I make, I might make Shepherd’s Pie, and I make 4 or 5 and put them in the freezer. So when I feel bad, like I don’t have to cook ‘em; I just have to put them in the microwave and I have a meal, that sort of thing.

I try to, think in my mind, what to do to help myself later when I’m not able to do it. Or the day I’m not able to do it. Because it’s funny days now because, part of the day you might have an hour you’re feeling fine, then all of a sudden the wobbling and that, you know, it happens, and you can’t do nothing – what can you do about it. I keep blaming it on the tablets, btu when you think, I think of it really it can’t be all the tablets. It’s the progress of what’s happening to me. You can’t blame it on the tablets really. it’s something that’s happening to me, and they don’t know enough about it to make it any better. And I’m sure I don’t decided to just abort the pills.

**Interviewer:**

**And just talking about your tablets, how do you manage your tablets?**

**Answer:**

I’m managing fine except it takes me at least half-an-hour in the morning to put them together and that, cos I have them, I think it’s about 19 tablets. And it’s then that I think, get the tablets container. It says take one three times a day say, so I put, get 3 out; put them in some things where they’ve gotta go; read it up make sure it’s the right one; and I’m over checking myself all the time. I did ask the, (PD specialist), if I could have them put into splinter packs. And he said yes, so he raised a note and that, but it hasn’t happened yet cos I haven’t needed tablets since that happened. But I think it will better. I’m always frightened I’m gonna take the wrong ones; too many of the wrong ones sort of thing now.

**Interviewer:**

**So, at the moment you do it yourself.**

**Answer:**

Yes

**Interviewer:**

**You lay it out in the pill box**

**Answer:**

Yes, do that. I generally start with that one, I do, but that’s one I have in the morning. And then the rest of them.

**Interviewer:**

**So, you take medication 7 times a day**

**Answer:**

No. I don’t use that one. The rest I use 6 times a day.

**Interviewer:**

**6 times a day. 19 different tablets that you remember at which times. And you**

**Answer:**

I always read it, what’s written on the box, you know the tablet thing. In case I mix it up. I can do it by memory. but I’m not gonna always do it by memory so, I think check it; check it on there. And when I do it, say 6 tablets or 1 tablet or whatever’s in there. I leave it there, and I bring the next one and do that and put it next to it till I’ve got them all done. But I don’t move any from that side, cos I’m frightened I might take the wrong ones. There’s so many packets I’ve got to use, but it’s like I’ve got to use it as I don’t know any easier way of doing it.

**Interviewer:**

**And how do you remember to take your tablets, or do you have any problems remembering taking your tablets?**

**Answer:**

Most times I’m alright cos I’ve got Alexa talks to me and tells me, machine. Like a little .. tells me .. so, I do it that way.

**Interviewer:**

**So, Alexa speaks out, okay.**

**Answer:**

Time to take your afternoon ones; time to take lunchtime ones and so forth.

**Interviewer:**

**And how often is that; how often are you taking medications?**

**Answer:**

Err, 6 times a day, yeah 6 times a day.

**Interviewer:**

**Yeah, and how, what, how did you think about using Alexa?**

**Answer:**

My granddaughter bought it for me to do it. And now she’s direct working, she’s coming this weekend actually. So, set it up so that if I want (daughter) I just say, ‘Alexa ring (daughter)’. And so, they can ring me. So, if I fall over, I get in touch with someone, sort of thing. They’re all very good, but they live too far away for it, to ask for their help, you know. So, she’s gonna do Alexa, and something else on Alexa, I don’t know. I said I’m not brainy for all this stuff.

**Interviewer:**

**And how do you manage your prescriptions?**

**Answer:**

Um, (daughter) generally does it on the computer now. I haven’t done it. I’ve done it with, I’ve watched her do it and that, but I haven’t done it. If I was doing it, I’d phone up the Doctors, who’s only a 2-minute walk away, so anyway.

**Interviewer:**

**And have you found any challenges with your medications or prescriptions over the years?**

**Answer:**

What do you mean challenges?

**Interviewer:**

**Well, anything that has been difficult to manage with medications.**

**Answer:**

Can’t really think. I don’t know if I have or not. I’ve had lots of problems with them. The wrong ones came once; hadn’t told me they needed to come in and of course (daughter) got them for me and I said, ‘I don’t take these’. It was the same name, but different strength, that’s it.

**Interviewer:**

**So it was, so it came from the Pharmacy with the wrong dose that you were taking, okay. And what happened then?**

**Answer:**

Oh (daughter) went up and saw them. (daughter) being (daughter), that’s enough

**Interviewer:**

**And how, you know, the medications have obviously changed over the years. Howe have you managed that?**

**Answer:**

Alright. It seems to be alright. The one at the moment that’s awkward, because I’ve been on 125 on it; on 100 on some and some are 75. And now they, last time I saw the Doctor, he changed two to 100, or where I had one at a 100, and the 75 I think its 3 or 4, 3. (okay) so you got it, and those two packets, even the tablets look the same.

**Interviewer:**

**Of course. It’s quite easy to get confused.**

**Answer:**

What confuses you is if you drop them down there now.

**Interviewer:**

**It all looks the same.**

**Answer:**

That’s right. You’ve got white ones; in the first one I have 3 white ones. And you try and see the numbers on that one and that one, that’s why I said about having the Splinter Pack. I did drop them once, and it took me about 2 hours to sort them all out, and the numbers and everything. (blimey yeah) I done it in the end but, I wouldn’t have taken them if I couldn’t have

**Interviewer:**

**Worked out which was which**

**Answer:**

No, that’s it.

**Interviewer:**

**So which medications do you take, do you k now?**

**Answer:**

I don’t know the names of them all.

**Interviewer:**

**Main, are they all for your Parkinson’s?**

**Answer:**

Yes, I got Cholesterol one, but I didn’t have. I was Diabetic or am Diabetic, but they gave me Cholesterol ones for it cos I was Diabetic, but I didn’t have high Cholesterol at the time, I remember that. so, it’s the Cholesterol ones. Oh, one for your bones. That’s the other one. I thought I had three different ones; not sure now will have to look at the box and see the tablets.

**Interviewer:**

**Yeah, that’s fine. And um, you talked slightly about the exercises. So, tell me about your experiences with, with those you’ve been given**

**Answer:**

Oh, they’re all very good. And I could do them now, but now I get too weak to do them.

**Interviewer:**

**Is this the exercise that was given to you be the Physiotherapists?**

**Answer:**

Yes (okay). Got a couple of lots of different ones.

**Interviewer:**

**How did they give you them, the exercises?**

**Answer:**

Well, they see if you can do such and such and things. Lay on the bed; lift your legs up; this one, that one and so forth. Or sit down; and move your hands with weights in it; stand up, so many things. I try to do ‘em but can never get through them all now, which is annoying.

**Interviewer:**

**And do you think they were helpful or not?**

**Answer:**

Yes, they’re helpful, and I’ve got the papers now and if I feel a bit comfortable I will have a go at them, when I can. Probably not as much as I should.

**Interviewer:**

**Yeah, and what stops you you think?**

**Answer:**

Well, if I’m not feeling right in myself I know it’s going to make me feel worse. To try and exercise and can’t breathe, one thing and another. Then I think I’d sooner do something rather than exercise.

**Interviewer:**

**And you talked about how, you know, day to day it changes how you feel. Do you think the medication makes any difference with that?**

**Answer:**

Yes, it must do, yes.

**Interviewer:**

**In what way?**

**Answer:**

Um, when I take the medication, I might be feeling horrible, and then 20 minutes or an hour and a half later it does. So, I always think it must be the medication that’s done it. It doesn’t go instantly, it might, as I say, take half an hour maybe an hour and I feel alright. Then instead of feeling dizzy or anything, I’ll have something else I’m shaking or something, you know. It seems the day’s always a challenge, there’s always something you gotta do to try and make it easier.

**Interviewer:**

**Yes. And do you, do you notice if your medication is, is running out or you’re due for your next dose?**

**Answer:**

Oh yes.

**Interviewer:**

**What do you notice?**

**Answer:**

Well, I might have the shakes; I might just be breathing, I feel horrible with me breathing and that. it’s all different things that happen. I can’t walk into the kitchen; I have to lift me feet up from, obviously do the ex, part of the exercise that you have some help relieve that.

**Interviewer:**

**And do you monitor your symptoms?**

**Answer:**

No. I should do, but I don’t. I’ve tried it a few times and I end up thinking, ‘oh, blow it’.

**Interviewer:**

**Why’s that?**

**Answer:**

Well, today you sort of monitor and you think, ‘oh, you’ve got the shakes, that’s 10 o’clock to 12 o’clock’, or whatever it is. And then you’ve got something else that’s starting up. I feel dizzy and that at a certain time. And I write it all down; then the next day comes and it’s a different time and that, and in the end you think, ‘well, what you doing it for it’s always different’.

**Interviewer:**

**Yeah Yeah. it’s not quite the same as**

**Answer:**

Yes, that’s right.

**Interviewer:**

**And um, tell me about your experiences about, you know, seeing your GP, about your Parkinson’s or if you’ve ever had to**

**Answer:**

I’ve had to see them, but I haven’t seen them since, since I’ve moved and because with the virus and everything, you know. Although I have got a telephone call next week, to the Doctor, to see how I’m getting on and everything.

**Interviewer:**

**Is that your GP**

**Answer:**

Oh, what it is, its, (daughter) reckons my mind’s going. And she said about it, and that’s what they want to see me. I think even that, although I got the thing to, the telephone call to say, ‘would I like to go ..’. I think how can they tell you when they haven’t seen you and knew how you were before.

**Interviewer:**

**So that must be difficult with,**

**Answer:**

Yes, that’s right

**Interviewer:**

**Covid. And it’s a telephone appointment is it, yeah? And have you had many telephone appointments?**

**Answer:**

I should think about 4. Not really sure.

**Interviewer:**

**And how do you find them?**

**Answer:**

Well, I know I’m talking to you now but, as a rule, I never think what to say until I’ve been off the telephone sort of thing.

**Interviewer:**

**And is that with your GP?**

**Answer:**

Yes.

**Interviewer:**

**And what about your appointments with Parkinson’s Teams. How have your experiences been with that?**

**Answer:**

They’ve been pretty good, yes.

**Interviewer:**

**And what’s helpful about them?**

**Answer:**

Well, they do explain things to you, you know, and when you know that something is happening all the time but it’s different from what you thought. I can’t think of anything, for example, for you. No, I’ll think about that in a minute.

**Interviewer:**

**That’s okay. And, um, and that’s the Parkinson’s Team that you see. You talked slightly about the Parkinson’s Nurse Specialist, have you ever needed to get in touch with them or see them?**

**Answer:**

Not since I’ve been here I haven’t got in touch with them. I have been going to a couple of times but haven’t. I don’t think I have anyway. When I was at home I did, cos I got to know them quite well you know. And they came round, different ones at different times, and they said, ‘we’ll try this and this and this’.

**Interviewer:**

**But it’s obviously changed since you’ve been here**

**Answer:**

Yes, that’s right.

**Interviewer:**

**Okay. And if, you know, if you had had a concern or question about your Parkinson’s, um, what would you do?**

**Answer:**

Most of it I leave, and I think it will be alright tomorrow sort of thing. But then, if it’s quite a while (daughter) says, ‘you’ve gotta do such and such a thing’.

**Interviewer:**

**Like what, what would she**

**Answer:**

Oh, she might say, get in touch with the Doctor or the Nurse or something. Find out what is happening.

**Interviewer:**

**You tend to try and leave it.**

**Answer:**

Yeah, I think it will go away tomorrow. I’ll be alright tomorrow, it’ll all go (giggle).

**Interviewer:**

**And err, um, have you had contact or access to other Healthcare Services. So, you know, district Nurse, Physiotherapist, Occupational Therapy, Speech Therapy or anyone else?**

**Answer:**

Um, what, I had a couple, but that’s talking about home again. Well of course it’s not home now but where I used to live. Trying to think; should have written it down. (giggle) Everyone I’ve seen has tried to help but, I sometimes think they don’t know any more than me. I don’t mean they’re not educated; I mean the disease itself is so different in different people. It’s, I can’t say, ‘oh, I’ve got such and such at 10 o’clock tonight’, but somebody else hasn’t got it sort of thing. They’d have something entirely different it seems. Then you think, ‘well, is it right? Am I right, should I be like that?’ ‘Am I doing something I; shouldn’t do?’ you just don’t know. Try to question everything, not that I’m good at questioning (giggle). I haven’t stopped talking have I?

**Interviewer:**

**No, no that, it’s very useful. And I suppose you, thinking about your appointments for your health care, for your health, how do you find getting to the appointments**

**Answer:**

(daughter) does it generally, as I said she’s very good. She, and I understand with her, she drives, she wants me to do more. But I understand also, that if I do more I’m gonna feel bad, sort of thing (giggle)

**Interviewer:**

**It’s trying to find a balance**

**Answer:**

That’s right, yeah.

**Interviewer:**

**So, what does (daughter) help you with, in terms of your health?**

**Answer:**

What, sorry?

**Interviewer:**

**What does (daughter) do to help you with your health?**

**Answer:**

Well, she takes me to all my appointments; she sees that I do have all, err, my shopping, because I had that before I had, came here, and even before I was diagnosed with, um, Parkinson’s because my husband’s bad, and I couldn’t get out, so I had it, in before the virus I was having deliveries for me foods, and that helped, um. And so that saved her also from coming round. And what else? She sort out, phones up people and tells people, and does me bills. Err, said I’m due to get them and that, although now, they’ve, delivered it one day and (daughter) couldn’t get them, so they delivered it to me, so now it’s got written on the thing, ‘delivery’.

**Interviewer:**

**Your medication?**

**Answer:**

Yes. That’s nice to have them. Cos I don’t like to rely on (daughter) although I know I do, you know, cos she’s, she’s got her own life. I appreciate all she does, and I love her coming round and I love her to bits. I’ve got two daughters by the way, the other one’s in Australia though.

**Interviewer:**

**Yes, of course, yes. Yes, you said.**

**Answer:**

We go on Skype every week and have a chat and see the grandchildren and the great-grandchildren (wow), which is nice. I can do that, but it seems I can do less of the things which I always think. If you’ve got something, what’s the next stage gonna be but nobody knows how you’re going to be. Don’t know yourself, and nobody knows as you say. (yes of course) Parkinson’s is a, I don’t know,

**Interviewer:**

**And have you looked up information about Parkinson’s or**

**Answer:**

Some things I have.

**Interviewer:**

**And how do you do that?**

**Answer:**

Um, it’s there (computer, yeah). It takes me a while, but I can get, you know, and ask them things. But sometimes I feel I don’t want to know. Cos I think, ‘oh, am I going to get that bad or will I be on me way before that’ or how am I doing now (giggle). You just don’t know whether its gonna stay as it is

**Interviewer:**

**And how was that, looking up information on the computer. What was that like?**

**Answer:**

A bit complicated at times, you know. Some of the words they said and that. A bit negative at times, cos the amount of things they can’t explain to you. I don’t know what that means, I know what it means in my mind, you know.

**Interviewer:**

**And, um, thinking about, you know, anything else that you do for your health. So talked about, you do some of the exercises, medications and the appointments, are there anything else that you do to help manage your health with Parkinson’s that we haven’t talked about?**

**Answer:**

Oh yes, as I say I have a lady come in and clean now; got a gardener come; who else I got? Me window cleaner comes, cos I just can’t do these things now.

**Interviewer:**

**So, you get people’s help to**

**Answer:**

Yes, that’s right, just think. I’ve got a cloakroom in there, but I want to get that changed but it’s knowing how to do it. Because, um, the shower is too high to lift in and a couple of times I’ve not tripped, but nearly tripped you know. Just saved meself in time. And err, and where I lived before, my husband, we had a shower put in that you could go, working. But now it’s deciding whether, I’ve got a little shower room, whether to have it in there or whether the main bathroom which has a proper bath in; bath taken out and one of those walk ones. The small shower room you can’t get the seat in to sit on.

**Interviewer:**

**To have a shower**

**Answer:**

Yeah, to have a shower, things like that, you know. I’ve got most of the walking things. Some, when my husband, he was ill will his heart and that.

**Interviewer:**

**Um, I s’pose, you know, what, have you had any financial expenses from the Parkinson’s?**

**Answer:**

No. Err, um, yeah I’m having a Carer’s one or something. Not a Carer’s. Oh dear, what do they call it? They call it something Carer.

**Interviewer:**

**Is it Attendance Allowance?**

**Answer:**

Yes, that might be it. Yeah that’s called that.

**Interviewer:**

**Yeah. But do you think you’ve had any financial expenses associated with managing your Parkinson’s that you**

**Answer:**

Well, I’ve done different things to help, you know, got different things. But you

**Interviewer:**

**What’s that for. What sort of things?**

**Answer:**

Helping me, like that trolley it’s a walking thing. I got a couple of chairs; I got one, they gave me it last time I was at the Nurse’s thing that you can put your meal on and push it along. They’ve been very kind, but its, nothing that I can think that I need sort of thing. Just manage your things. And if you see anything. I was saying when my husband was bad, ill, if there was something that could help him we would try and get it. Fortunately, I have a Pension off my husband’s works so, you know, that helps with things.

**Interviewer:**

**Yes of course. And, just thinking about, um, you know, whether you’ve had any issues getting help over the weekends or overnight?**

**Answer:**

No, the only other issue like that, I’ve found they won’t give you their names. Um, I was at home, at me other home where I live, and I had a phone call at ten past eleven at night. Answered the phone; thought who’s this, you know; was just going to go up to bed. And they said they were from the Hospital. I’d had a blood test, and they were worried I had a, err, um, a clot. And he said, ‘oh do you, get you tested as soon as possible’. So, I thought, ‘yes’, cos our sister-in-law died of clots funny enough, you know, so I knew what it was all about.

So, I had to phone up a Doctor, he gave me the Doctor’s name and I phoned up the Doctor. The Doctor wasn’t happy coming out, but I said, ‘well, I can’t get to the Hospital’. (daughter) was away on holiday at the time, so I can’t get. So anyway, they gave me another Doctor’s phone number and I phoned the Doctor, and he didn’t want to do anything. I said, ‘what’, and she said, ‘what do you want me to do’. I said, ‘I want to be tested’. So, they got a dep, they got another Doctor to pick me, well an Ambulance to pick me up to take me, but he wasn’t happy because I was using an Ambulance, you know. But there you go.

**Interviewer:**

**And that was, so what happened after that?**

**Answer:**

Well, I got in the Ambulance; went into the Hospital; sat on a chair half the night; and Doctor called me, or somebody, no a Nurse come and said, ‘have you seen a Doctor?’ I said, ‘no’. the Doctor called me up there; asked the Nurse to me, to go and have a word with him. And he looked me in the eye very close. He said, ‘listen to me, you have not got a clot’. I thought, ‘well how does he know I haven’t got a clot, cos he hasn’t done nothing anyway’. So, I thought anyway, the Doctor, my Doctor, I saw him the next day and I explained. And he was apologetic before I walked in the door, so he knew something had happened. I thought, ‘well there’s no need for it’. The Doctor at the Hospital said I got to have it; cos they were worried I had a blood clots, and yet they’re saying, ‘no, go back to bed’, sort of attitude. Well, I thought I wouldn’t have gone up the Hospital anyway if I thought all was well.

My Sister-in-law died of blood clots; you know. Cos she’d been on holiday and ignored it and everything, and then she passed away, so I thought If it’s that had to take it serious. Of course, at the time I was a bit worried I shouldn’t have done it. Cos that’s not me to make a fuss over things, and I thought, ‘well if I done, and it is wrong, does it matter?’ its better to be safe than sorry. (yes absolutely) But that’s the only time I felt annoyed but that the Pharmacy, not the Pharmacy, the one who takes the bloods sort of thing he phoned me up. And get to

**Interviewer:**

**Get to the Hospital.**

**Answer:**

So, that’s that.

**Interviewer:**

**And, have you had any, you know, experiences in Hospitals with your Parkinson’s?**

**Answer:**

Um, not really, no.

**Interviewer:**

**Have you ever been to Hospital; been admitted to Hospital or?**

**Answer:**

Yes, twice in the last month, six weeks.

**Interviewer:**

**Oh dear. And what’s happened there?**

**Answer:**

Well, I was lucky. My granddaughters were both here, they’d come to see the place, the first time, you know. And (daughter) was here, we’d had a meal out; come in; we were just sitting in the other room chatting together. And I thought, ‘oh, I didn’t put them’, I had one of them walker things in my second bedroom. ‘Oh’, I thought, ‘I hadn’t taken that out’. ‘I thought if my two girls are gonna stay the night, they might trip’. So, I went in to go into them, and just blanked out. I remember when I went banging me head. And apparently it was pouring with blood and I had a funny scratch there. They had to put, not stitch it, put some gluey stuff on it. And then I went home the next day.

And, um, the last one, funny again. My nephew came down from Wales, cos I hadn’t seen him since before the virus and he popped into see me which was a big surprise. And err, I was ill then. I felt funny. Now to say you feel funny, it’s stupid what did you, no-one could get any answer out of that. so, I said, ‘I’m not feeling as I generally do, but I’m dizzy and that’. I rang 111 and told them the things, they said they’d have an Ambulance down. And I thought ‘not again’. So, they sent the Ambulance round, and I went into Hospital. They did the usual things; your blood; and all your things. but it went, they didn’t say what happened, but one Nurse said to the other, ‘oh look at this now’. At the time me blood pressure was up and down and everything, it was very low most of the time. Cos they thought there’s nothing wrong and then they said, but they never, ever said what, look at this was, it was amongst themselves. So even now I don’t know what they were looking at, just felt better afterwards and everything was alright. And you go home.

**Interviewer:**

**And how was your Parkinson’s, what managed while you were in Hospital? So, what were your experiences with that?**

**Answer:**

Well, I took me tablets meself. And I prescribed things meself. I did say one time, you know, that. Cos it’s alright if you know what you’re taking. So, as I was taking them out each time, next day it didn’t really matter. I don’t want to go in anymore I think (giggle)

**Interviewer:**

**No let’s hope not**

**Answer:**

Not that there’s anything against them, they’re all very kind. They’re all overworked and

**Interviewer:**

**And what was your experiences of calling 111 you said?**

**Answer:**

Well, I hated it

**Interviewer:**

**Oh dear, in what way?**

**Answer:**

Just having to phone up. I’d done so much for that with my husband, cos he was on his, palliative, or something, when you’re on your last. He was on that a long time and, of course even (husband) he’s like me, he wasn’t. He didn’t want the Doctors or anything to make a fuss; he didn’t want to see the Doctor, but of course I was on the other leg then. I was doing what he’s doing, or he’d done.

**Interviewer:**

**So, you just didn’t want to call for help did you? So, what made you do so obviously?**

**Answer:**

What, with myself (yeah, 111). Well, I knew there was something wrong, but I didn’t know what it was. I was shaking; I was out of breath, could hardly breathe. Obviously me blood pressure was going low and that, and down sort of thing, and things like that. But, although I knew something wrong, I didn’t know what it was. Which, you can get feelings and you think, ‘oh, starting again’, sort of thing what it is. But this wasn’t, and that’s when I think I’d better have it checked out, you know. And the only way to do that is phone them up.

**Interviewer:**

**And was that out-of-hours or?**

**Answer:**

Yes. Evening time as usual (giggle)

**Interviewer:**

**And I s’pose thinking about, what are your thoughts about how your care, how your health care has been co-ordinated between, you know, Parkinson’s team; the GP; the Hospital**

**Answer:**

Well, I don’t really, I dunno what to say, um, how would you put it. When I’ve called them I’ve been alright, but I haven’t really called them as such. Cos being here such a short time, and its no good going back to where I lived before and what it was like

**Interviewer:**

**Its difficult here, having as you’ve just moved here (Yeah). Yeah, I suppose, you know, what do you think helped you cope with all the things that you do to manage your health. So, we obviously talked about the medications, the appointments, the exercises.**

**Answer:**

I think you; this is how I do it at least, dismiss a lot of it. Get on with it; think it’ll be alright tomorrow (giggle). And if you, if it wasn’t what I had today, tomorrow its something different so, you, that’s the only thing you can do. Life, well, that’s so like. I know, in my mind, that if I had something wrong I would get help from any of them, although I haven’t seen them toge. What they do have at the Doctors now, I, they’ve just started, is they’ve given you a Doctor if you’re over 75 and that takes, you know it’s your Doctor. You can phone the Doctor up or the Nurse up at time, any time sort of thing. It’s as if it’s your private, I know it’s not your private line one, but it’s as if eld, health, help is always at hand.

**Interviewer:**

**That your GP?**

**Answer:**

Yes. They’ve just sent me a letter about a month ago for that, and that sound, very interesting. They’re trying to co-ordinate you together with one person, so that person gets to know you and you will get to know them.

**Interviewer:**

**Yeah, that sounds very helpful.**

**Answer:**

And so, I think that’ll be better.

**Interviewer:**

**Good. Um, I know you were talking about getting help from Carer or gardener or cleaner. Do you have that any paid Carers to help you with personal care?**

**Answer:**

No

**Interviewer:**

**And are you aware about where to get information about getting more help if needed.**

**Answer:**

Um I suppose I’d have to get in touch with some of the Health carers and speak to them.

**Interviewer:**

**Yeah, and how would you go about doing that if you need to?**

**Answer:**

I suppose by appointment with someone. The Doctor or someone I’d say ‘oh can we…’

**Interviewer:**

**How can the Healthcare System be changed to help you manage your health with Parkinson’s? what do you think?**

**Answer:**

Let you know more, I should think

**Interviewer:**

**In what way?**

**Answer:**

Well, if you got a worry about something, you gotta know why, what’s causing it; obviously they don’t know themselves half the (giggle). I don’t mean that nastily, I mean you haven’t got the data to see it. But I think people would be happier in themselves if they knew a bit more what was going to happen to ‘em.

**Interviewer:**

**And is that some information that you wish you know about Parkinson’s or not personally?**

**Answer:**

Not personally, because I did think, until I read a bit, well is that going to play on me mind and make me feel worse the fact that I know what’s going to happen. If that’s the case, you might as well not know.

**Interviewer:**

**Yeah, absolutely. And is there anything else you’d like to add that we haven’t talked about, you know, in terms of looking after your Parkinson’s and what helps, the things that help you look after your Parkinson’s. So, we had a couple**

**Answer:**

I don’t know really. Cos with my husband, they used to come and see him and everything, and suggest things that might them, help him rather. But I can’t think of anything. Going through with him all, I can’t remember anything I needed at the moment.

**Interviewer:**

**So, you compare your experiences with Parkinson’s to your experiences you had with your husband**

**Answer:**

Yes. Cos he was ill a long time and, well I didn’t have to look after, I wanted to look after him. In fact, at the end he wanted to go in Hospital cos he was worried about what I was having to do, you know.

**Interviewer:**

**And did you have Parkinson’s when, did you have Parkinson’s diagnosed by then**

**Answer:**

Yes, it was diagnosed before he passed. Yes, and he was worried about me and I was worried about him, sort of thing.

**Interviewer:**

**And how did you manage your Parkinson’s at that time?**

**Answer:**

It wasn’t so bad. I didn’t feel so bad in myself; I could cope. I didn’t have all this shaking and things going on, cos that’s why (daughter) harps back to the pills I had before. Cos I was a lot better on them meself, but I think it’s just the illness has progressed.

**Interviewer:**

**Yeah, so (daughter) thought you were better on the older tablets (yeah). And what about yourself, do you agree with that or.**

**Answer:**

Yes, yes, she was right. I was better. But whether if I changed them all, I’d go back to how I was, I don’t think so. I think it’s just the illness itself has progressed.

**Interviewer:**

**Yes. So, you think if you did change back to your old medications, it would be the same**

**Answer:**

Yeah, I know that sounds a bit daft but

**Interviewer:**

**Yeah, yeah. And do you think the current medications are helping your symptoms?**

**Answer:**

Well, it’s silly. Cos sometimes I feel like. The last couple of days I’ve felt, oh, I’m feeling a little better, but then I get halfway through the day and I feel worse. So, I thought, I can’t say they’re doing me any better or making me worse, it’s just, I don’t know. Something you’ve gotta work through in your mind I suppose.

**Interviewer:**

**And do you ever change your medication doses without telling anyone?**

**Answer:**

No. Generally, the Doctor. I am on two of the first ones, stats something, these two, a hundred ones. And I was on 75 so the Doctor said go onto two, two of the hundreds, not just one of the hundreds.

**Interviewer:**

**Is there anything else that you’d like to add?**

**Answer:**

No, do you want a cup of tea or water or something

**Interviewer:**

**No, that’s great. Thank you very much for that.**