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| * Diagnosed 3 years, PD dementia 2 years * Wife caregiver + daughter * Does not drive |

**Interviewer:**

**So, I’d just like to start by asking some generic questions about your Parkinson’s. so how long have you been diagnosed with Parkinson’s?**

**Answer**

I think it was something about 2017 -2018. Um, it’s something that’s, it sort of came on slowly from what I can recall. Um, it’s something I find, it’s um, you have to excuse me, it’s part and parcel of how that gets to me. I have to stop and, and err, sometimes I lose actually, the actual train of thought.

**Interviewer:**

**That’s absolutely fine.**

**Answer**

So, you’ll have to excuse me.

**Interviewer:**

**No problem at all.**

**Answer**

Um, as I say, the thing is something about 2017-2018. And, um, there was a sort of, um, it got to a point, sort of thing, that there’s things like driving; I’ve had to stop driving because, um, I just can’t cope; my reaction time is a lot slower. Um, and err, its err, well it’s actually, it actually feels. I, sorry, I’ve lost it. Um, but err, yeah, it’s something I wouldn’t wish on anybody, sort of thing. It’s a, um,

**Interviewer:**

**So obviously it’s been quite challenging since your diagnosis by the sounds of it**

**Answer**

Yes.

**Interviewer:**

**And what do you find, you know, since your diagnosis. What aspect of looking after your Parkinson’s do you find most difficult or challenging?**

**Answer**

Um, quite often, like now certainly, the voluntary sort of shaking. Um, there’s certain jobs, around the house, that I can’t do anymore. Um, I used to do quite a lot of DIY, and everything like that. Um, so, climb up a ladder; clean out guttering and things like that. I can’t do that now. I can’t go up ladders. Um, it’s about, it prevents me safely going up there. And something like, an electrical job where I might want to, to put a, um, 13 AMP plug onto a piece of wire so I might get an extension out. Um, I can’t, can’t wire up a plug; three wires and I can’t do it because it’s, I haven’t got the control to do a simple job like that. Um, it’s infuriating to say the very least. And, yeah, infuriating is the polite way of putting it (giggle).

**Interviewer:**

**Of course. And thinking about what you have to do, or what advice or treatments you’ve been told to help with your Parkinson’s. do you find any of those, um, what do you do to help with those, with the, you know, the Parkinson’s and what have you been told to do?**

**Answer**

Um, basically I rely upon my family. Um, my, my memory for going back a long way before I retired and things like that, um, is still quite good. Now, um, it, if I’m talking to you sort of thing, um, err, um, I forget where I get to. Um, though, as I say, it’s infuriating the polite way of putting it. But I rely upon, um, my family. My wife is a godsend. And I have quite a few tablets to take, um, for both the Parkinson’s and I have had a procedure done on my heart because it’s, its lost the correct um, um pulse. Um, so there’s quite a lot of medication and, um, my wife basically um, makes sure that the tablets are there for me to take when I need them. And say that is something, um, I’m not sure that I would be able to cope without it.

**Interviewer:**

**So, she helps you with your medication?**

**Answer**

Yes.

**Interviewer:**

**How does she, what does she do to help with that?**

**Answer**

Well, we work with Lloyds Pharmacy, um, and, um, my wife or my daughter will actually use the internet to actually order the drugs. These are then sent to us through the post so, and it is there for us. Um, a, I find it a bit difficult at times um, to um, identify the actual drugs themselves, um, but, it’s as I say, she sort of sorts out the actual tablets in a little dispensing tube

**Interviewer:**

**Blister box or something**

**Answer**

Yes, sort of thing. I think there are 7, a whole weeks’ um, err there, and um, she will then sort of sort these tablets out, um, for me. And then, um, will have the actual drugs, um, we’ve got an alarm set for certain times so that I know the next time when I’ve got to take the tablet. So, that as well. Um, we’ve come to a little bit of a glitch, um, when we actually had the, um, the time go back an hour. These little electric, um, things, um, we got um, I thought I could sort of, um, put the time back. Um, both my wife and I tried; we were waiting for my daughter to turn up on Wednesday. Um, but err, yeah, as I say, infuriating. I’m not very good with computers anyway. I’m lucky in that respect because my wife has a bit more know how than I have.

**Interviewer:**

**Is that electric timers you’re talking about?**

**Answer**

Yes. Yeah.

**Interviewer:**

**And is that a little device on its own?**

**Answer**

I’ll show you.

**Interviewer:**

**Yes, certainly, that would be great.**

**Answer**

It’s programmed at this time to go off, and I cancel it by that button there.

**Interviewer:**

**So, it’s programmed with med, alarm, along with the medication box**

**Answer**

That’s right.

**Interviewer:**

**That’s quite clever.**

**Answer**

And it, err, good, reminding you when you’ve got to take your tablets. But you usually find, if I’m out here, it’ll go off in the lounge. Or if I’m in the lounge it’ll go off out here. It always goes off at the wrong blinking place (giggle).

**Interviewer:**

**So how many medications do you take in a day?**

**Answer**

Um, (do you know?) basically, between sort of the Parkinson’s, um, I’ve got a sheet if you want to see it.

**Interviewer:**

**You can show me later, no, you’ve only just got up and down. Do you know how many times a day you take the medications?**

**Answer**

Yes. There’s 2 which I take about half past six in the morning. And then there’s um, a morning one which there’s Parkinson’s and um, water tablets. Um, and then an afternoon, which is err, um, heart related and then there’s one in the evening, about half past seven at night and that’s then all sorted out. Then to, sorted out ready for next day.

**Interviewer:**

**And how do you find taking the medications?**

**Answer**

Oh no problem. as long as I know what I’m taking. Um, as I say, taking the tablets is no problem at all.

**Interviewer:**

**Good. And, um, I suppose thinking about, you know, any other things that you do to manage your health. You talked about, obviously you talked about medications to help with your health. Um, are there any other things that you do to try and manage your health with Parkinson’s?**

**Answer**

Try and go out for a walk. Um, I’ll go round the block. I don’t know if you know this area (not very well), not very well. Um, go out the front door; up to the (road name), I can actually walk a square sort of thing, brings me back to the top sort of thing. Um, I try to do, um, a lot, walking, exercise that way. Um, (wife) will come out with me sometimes, or we will go out for walks somewhere different, cos she likes her walking, that’s her therapy she has; gets her out of the house.

**Interviewer:**

**So, going for a walk. And is that something that’s been recommended to you or something you just thought to do?**

**Answer**

Yes, it’s been recommended to try and have at least one walk, or two walks presumably you exercise that way.

**Interviewer:**

**And who recommended that, you know, exercising and walking?**

**Answer**

Um, don’t know. The lady who, um, does exercises with a group of us, err, people. I’m not sure if they all have Parkinson’s, but, um, I know Wednesday, um, we’re doing some sit-down exercises and err, spend an hour with her. Um, unfortunately she’s been diagnosed with, um, breast cancer, and she’s got to have an operation in a few days’ time, so we’ve lost that. But, um, somebody we talk to about exercises and thing like that.

**Interviewer:**

**And who organises that? Is that the local town?**

**Answer**

It’s something we’ve found that um, I, something my daughter set up. Um, um, I think it’s something, it’s open to the General Public, if you know, should you want a bit of exercise. But it’s it’s nice, you know you learn sort of different exercises. Um, and err, sit and stand.

**Interviewer:**

**Sit and stand, yes. And how do you find doing the exercises?**

**Answer**

Oh, I quite enjoy it. Um, but err, as I say it’s something now that we possibly might not be able to do it until the new year. Just have to go and see how it goes.

**Interviewer:**

**Yes, of course. And just thinking back about, you know, when you were first diagnosed with Parkinson’s how did you get information about Parkinson’s and how did you find that?**

**Answer**

Um, again something that, um, I think my wife and daughter saw things that when I was actually first identified. Um, I had various tests done, like being able to smell things. The Doctor, um, would actually put a little, um plastic strip into um a solution had nose to it. Can you smell anything from that? Um, what can you smell? And quit often, no, couldn’t smell a thing. And (PD specialist) said that’s one of the things that identifies that identifies that you’ve got Parkinson’s because you lose smell.

**Interviewer:**

**\*Bring back sheet with medication names and times with pictures of medication boxes\* And so (your daughter) has taken a picture of all the boxes of medications.**

**Answer**

That’s right.

**Interviewer:**

**Oh well, that’s very clever.**

**Answer**

Will that be of help to you?

**Interviewer:**

**Yeah. so you take, um, 1, 2, 3, 4, 5, 6, 7, 8, 9, so 9 different medications.**

**Answer**

Yes, I suppose it would be.

**Interviewer:**

**Yes, um. For your Parkinson’s you take it 1,2 3 times a day for your Parkinson’s**

**Answer**

Yes. That’ll be increased to 2 tablets each time.

**Interviewer:**

**You take, but you take all your medications 1,2,3,4,5,6 times a day, different tablets**

**Answer**

It would be

**Interviewer:**

**Yeah. so, you’ve got, um, some medications. So other than Parkinson’s you’ve got your heart condition (yes). Is there any other medical conditions that you have?**

**Answer**

No, not now.

**Interviewer:**

**…That’s very useful.**

**Wife**

You’re welcome to have it if it’s any help to you

**Interviewer:**

**Oh no, no, no, that’s absolutely fine. That’s very useful. Um, I suppose the other question is, you know, how have your experiences been, um, you know, with Healthcare Professionals about your Parkinson’s?**

**Answer**

Um, I think it’s been excellent. No, I found sort of, not only the Parkinson’s people, but the other, um, Doctors and Nurses that, err, I’ve come across have been absolutely brilliant. I couldn’t really wish for a better bunch of girls and boys.

**Interviewer:**

**And what has been, you know, what has been really good about your experiences. What do you think has made that so positive?**

**Answer**

I think it’s the way that they conduct themselves. Um, and they do their jobs but do it in a way that’s um, pleasant shall we say. So, yeah, a say, couldn’t wish to be, or come across these wonderful people.

**Interviewer:**

**And how many appointments do you have for, err, your Parkinson’s in the last 12 months?**

**Answer**

Um, I think it, we’ve seen (PD specialist) about 3 times, but we’ve, I’ve got a contact telephone number and if we needed to I’m sure that, um, we’d actually get in contact with someone from Parkinson’s Group, um, if we had any problems.

**Interviewer:**

**Have you had any problems that you**

**Answer**

Well, the only thing that comes to mind is when, is it, Co-Beneldopa, Parkinson’s

**Interviewer:**

**Co-Beneldopa, yeah**

**Answer**

Um, we sort of wanted to increase that cos, um, sort of my wife and daughter thought it would be better for me to have some tablets, rather than take one tablet at a time, but they got in contact with us and increased to two tablets 3 times a day. So, each of the actual tablets themselves, um, but um, but increased. I think it helped, to um,

**Interviewer:**

**So, did you, your wife and daughter noticed it and thought you needed bit more medications**

**Answer**

Yes

**Interviewer:**

**And then they contacted, and contacted, um, (PD specialist) team**

**Answer**

Yes

**Interviewer:**

**To see if he would agree**

**Answer**

And they did

**Interviewer:**

**Okay. And did you notice that whether you need more medications for your symptoms. Did you notice?**

**Answer**

I think it seemed to give me a little bit of sort of extra sort of, um, sort of, um, I wouldn’t have, energy is not quite the way of doing it. Um, I think it helped basically in my mind to be able to do things. But there are times that, um, I find that I’ve been doing something, and I sort of stopped. And I’ll sort of, um, freeze if you like. So (wife) was saying, ‘now what you thinking about’, sometimes I can answer her, other times I’m not too sure what I was thinking. Um, and err, I think in that respect these tablets have helped me to do a bit more. Um, putting things together a bit more, um, that the way to describe it.

**Interviewer:**

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

**Answer**

Not really, no. it’s just one of those things, you know. I get on with it. Um, as I say, there are times when I think that, um, I find it. I’ve lost my train of thought.

**Interviewer:**

**That’s okay. Um, have you had any contact, you know, with other Healthcare Services – Physiotherapists or Occupational Therapist or Speech Therapist, um, other than the Parkinson’s team or GP?**

**Answer**

Um, yes sort of the tests for memory and things like that.

**Interviewer:**

**Oh yes, is that the Older People Mental Health Team?**

**Answer**

Um, yes it would be. I’ve had it about 3 times. See how I’m progressing, um, and those, there’s something else, can’t think what it is. I, I had to have a polyp removed from my nose, swollen up and it was stopping me from breathing. Um, that’s been done, sorted out. Um, now I’ve got some problems with my, the eyes, at the moment. Um, I’ve, still waiting to be seen and have had some medication. They’ve tried different ones for my eyes, but the eyes water, get crusty, in, in the mornings.

**Interviewer:**

**Dry eyes.**

**Answer**

Yes.

**Interviewer:**

**And um, how, how has your memory been. I know you, when were you diagnosed with Parkinson’s dementia?**

**Answer**

As I say, my memory going back to say before, um, before I retired, um, was quite, quite good. Um, but since the, I’ve had the Parkinson’s, I’m aware of actually memory, um, is quite forgetful in, you know, doing different things. Um, the, yeah, I’d say it’s, here and now sort of thing, my memory is, can be at times, pretty bad. Um, my son said could be do this, and what was it you said, yes, repeats it. Or I’m doing the washing up, or something (wife) to the washing up, and I do the drying up. And I’d say, ‘I’ve forgotten where this goes’. ‘Open that cupboard up there’. Okay. So, its short-term memory, not very good.

**Interviewer:**

**And how has that affected how you look after your Parkinson’s. do you think it’s had an impact?**

**Answer**

I think the Parkinson’s has definitely had an impact on, to be able to do things. Like washing up, that’s just a very good example, but there’s, (noise)

**Interviewer:**

**Infuriating, is a term as you say**

**Answer**

Yes

**Interviewer:**

**Okay. And um, I suppose, learning about Parkinson’s, how have you found, you know, you’ve been diagnosed now for about 4 years. How do you find information about that, and how has that been in the last few years learning about your Parkinson’s?**

**Answer**

What, do you mean, different organisations?

**Interviewer:**

**However, you’ve gotten information about Parkinson’s. Whether, whatever you’ve done to get information, or has it been given to you?**

**Answer**

Um, it has been given to. Definitely time has gone on, um, what the next point it

**Interviewer:**

**Yes, something happened and then**

**Answer**

Someone’s been in contact with somebody (name’s) seen it on the internet, something like that. I know there’s been, um, something’s happened. I can’t think.

**Interviewer:**

**Yes, that’s fine.**

**Answer**

Sorry

**Interviewer:**

**Do you look up information on your own?**

**Answer**

Not on my own, no.

**Interviewer:**

**You wouldn’t, okay. Fine. And have you had any issues, or needed to get help, at the weekends or overnight so far?**

**Answer**

No.

**Interviewer:**

**Um, and thinking about, you know, how your care has been co-ordinated between your GP, your Parkinson’s teams and any other Therapists or Nurses. How do you think that has been so far?**

**Answer**

So far, um, it’s now. Um, when I’ve come in contact with different people, or groups of people, um, they’ve been good.

**Interviewer:**

**Good. Um, do you, so obviously you said (wife) helps you and your daughter helps you**

**Answer**

Very valuable

**Interviewer:**

**Yeah, and do you have any other Carers or care that helps support you, so your family you have mentioned**

**Answer**

No.

**Interviewer:**

**And have you ever had any financial expenses associated with looking after your health?**

**Answer**

Um, well I suppose the, err, situation. The garage at the moment. We’re engaged in the process of actually converting the garage to, um, a downstairs area for me. Um, we’re going to change it to, um, an occasional room

**Interviewer:**

**A what**

**Answer**

Occasional (okay) room so that, um, I can if I need to later. At the moment I can go and downstairs, um, alright, but there’s going to come a time that, err, I’m not going to be able to go upstairs. Um, so, this room, prepare it for, um, an occasional thing. Um, going to have it somewhere my grandson can, um, play on an Xbox or something like that. Um, I tried it; he said, ‘do this, that, grandad’. Ah, crash, crash, crash go the cars (giggle) Ucon. Um, but err, yeah the whole idea is to convert it to a room that we can use for anything. Um, and if we have any guests, um, you know, we’ve got an extra area that can be used, um, for sleeping purposes cos we’ve got 3 children. My daughter lives up in (city); my middle child is male, and he lives up in (City) And another one lives in, err, (city) So, there are times when it’s nice for them to come down to us, um, them to get away to the seaside, and for us to have a, to be able to see them.

**Interviewer:**

**Yes, of course. And is that something you worry about, your future with Parkinson’s and, you know, you said you’re thinking back. What concerns you?**

**Answer**

Well, how much I’m going to be, um. I worry that there’s going to get a time that I’m not going to be able to look after myself, and I’ll become to be a burden. And that worries me. And of course, it’s been quite a big expense so far to get to where we are with this garage conversion. But it’s something that, um, I’ve got no control over, just got to accept it. I try and make, there are times when I can get a bit flippant and, I try to put a lighter side on things. Um, so used to be sort of, talk to people quite fluently now. It’s something that has been pointed out to me a number of times, I’ve been talking and I’m liable to non-participance shall we say. Um, I, they had a little party for this lady who had to give up the exercise classes due to breast cancer and there’s 4, 5 people there. They were talking, different bits and pieces, um, and I was quite enjoying myself listening to them. When they were leaving someone said, ‘why didn’t you say anything?’ ‘I don’t know, why didn’t is say anything’. This is where you’ve changed. Um, so, I mean I feel quite comfortable sort of, um, just listening but nor participating in conversations like that. That’s an example.

**Interviewer:**

**And I suppose, thinking about what you do for your health. So, we talked about, you know, exercising and going to classes and walking, taking medications, and going to different appointments. Is there anything else that, you know, we haven’t talked about, um, that helps you manage your health?**

**Answer**

No. Nothing comes to mind. I’m sure there is, but nothing comes to mind.

**Interviewer:**

**And what things have helped you deal with, you know, what we’ve talked about so far?**

**Answer**

I think the only thing I can think of is basically is the support I get from my family. Um, nothing else sort of comes to mind, but I’m sure there is but

**Interviewer:**

**But do you feel overstretched by what you do to look after your health?**

**Answer:**

No. I’m sure there’s quite a, quite a few bits and pieces I could do to help out.

**Interviewer:**

**That’s fine. And I suppose, you know, how do you think the Healthcare System could be changed to try and help you manage your health and Parkinson’s, if there is anything**

**Answer:**

Very good question. The only thing I could think of is, I don’t know. (giggle)

**Interviewer:**

**That’s fine. (giggle) No, um, that’s great (name). That’s that’s, you know, very helpful, um**

**Answer:**

I hope it is.

**Interviewer:**

**No, that’s been very helpful.**