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| * Moved to area recently * Interaction with GP and HCPs therefore delayed due to COVID * Small flat, PwP also present at interview (with separate interview too) * Loss of daughter |

**Interviewer:**

***So, (name) obviously talked about how long he’s had Parkinson’s and all that, but again, you know, he mentioned a little bit about, from your point of view, about the information, um, that you both got. But from just your point of view how was that, how did you feel, how did you get the information. How was that?***

**Answer:**

At the first, at the very beginning I thought we were completely left really. We came out of the Consultant’s room and it was like wow. There wasn’t anything really. The Doctor wasn’t providing anything, it was just, you know, go to your Consultant. So, really I did feel very left alone with it. Um, so both of us, and we knew nothing about it really other than our friend shaked a lot and things happened. We didn’t know about the speech, um, that people have the freezing people had. We didn’t know anything about that at all, so it was, it was very, I felt, I suppose we thought we’d just get on with it somehow. You know, each day at a time; see how we got on. The only thing I did not want to do was, I did ask the Consultant, ‘will moving make a difference to (husband)?’ And he said, ‘only slightly, it shouldn’t be too bad’. But of course, when everything else happened it was, it’s not surprising really, you know cos we’ve been through an awful lot. I sometimes forget what we’ve actually been through. Um, so that, I think (husband) health ..

**Husband:**

Yes, and the moving and *(previous city name)* as ..

**Answer:**

Oh, I was just about to say, then when we moved there, that was the turning point. We got to know so much. It was so interesting, fascinating. Um, the only thing I don’t like is when they send the Parkinson’s Brochure out. And there was one last month, or whenever it was last, there was this man in a wheelchair sort of like this, you know, and his wife’s there and I said, ‘God that’s uplifting’. (giggle) He looked awful. And I thought if that’s the first person, the first magazine a person gets, he’s pretty awful. Um, cos you have to be a little bit uplifting about it don’t you, otherwise its, you know. Um, so, we try to put a bit of humour in it if we can and just support him as much as we possibly can.

**Husband:**

Cos the Parkinson’s Group not only did the people with Parkinson’s benefit but all the Carers.

**Answer:**

Oh God, yeah

**Husband:**

.. to each other

**Answer:**

Amazing. I couldn’t thank the OT enough. And she said to me, cos at first she, we didn’t really want to say that we’d just lost our daughter, but we did, she did know, didn’t she? And she just said to me ‘we think you’re so brave coming anyhow’, and I said ‘well, thank you’. And um, but towards the end I just felt all the people that were there, you know, they had illnesses of their own and they were trying to deal with their partners and that. So, you, it was really fulfilling, you learnt so much.

**Interviewer:**

***And just remind me how long after you were diagnosed that you went to this school?***

**Answer:**

It was, we were diagnosed in the June and we moved there the following June didn’t we? So there about 9 months we didn’t have much information or help. Only the lady at *(city hospital)* did say, ‘I’m here if you need me’, but we didn’t know what we needed her for cos we didn’t know what was in front of us. You know, they didn’t say, well this is going to happen; that might happen this, they didn’t do any of that. You, you just said, ‘yes (husband) you’ve got Parkinson’s, thank you very much’. And that was it. So, it was pretty

**Interviewer:**

***Did you look up information yourself?***

**Answer:**

You did, and we started to, but I don’t do the internet. I don’t really like it very much and (husband’s) when he does do it a lot of is rubbish, you know, well we all know that. So, you do start. So, it’s a bit like if you look at the symptoms you can get on the back of a packet of pills you wouldn’t take them if you read it all. So, from that perspective. We knew enough didn’t we from knowing (husband).

**Husband:**

We gained a lot of knowledge in the last few years.

**Answer:**

I would say that the biggest thing is talking to people, and their Carers.

**Husband:**

Absolutely

**Answer:**

You learn so much. Things, things I never knew existed about Parkinson’s so that, that to me was. That Group I think should be all over the country for everybody, I really do. And I think not only does it help the person that’s got Parkinson’s because as a Carer, not for me personally, but for some Carers who are not well themselves and are struggling. I mean we have a friend that, she’s very ill with Cancer, and she’s very very ill. Now her husband needs to get up in the night to go to toilet and he gets up and he can’t move; he freezes. And she’s awake most of the night worrying whether he’s going to get to the toilet and back again without falling. And I think they’re, they’re the people that need the help, you know, so it’s difficult.

**Husband:**

He told us a funny story. He plays golf or used to play golf and he’s got one of electric buggies. He pressed the button, buggy went, and he couldn’t move. He kept falling down on the green.

**Answer:**

He freezes, and they’ve suggested a light in the hospital. You know, to put the light and it gets him going. But what was funny was, if you were in a meeting and there’s all of you like this, he’d get up and he’d be ‘err’ and he’d shoot across the room. (giggle) it’s just, but you don’t know any of these things.

**Husband:**

I think really for any illness or disease like this, it’s really good to have other people that’s got similar experiences to get together.

**Answer:**

Yeah.

**Husband:**

You know what I mean, it could be anything not just Parkinson’s.

**Answer:**

Well my friend’s got Cancer and when she went to the Hospice she found that so invaluable talking to other people. Cos talking to me, I didn’t really know, so I think it generally

**Husband:**

The social aspect can be quite, you know, helpful.

**Answer:**

Yes, I think so as well, um.

**Interviewer:**

***And that was run by Parkinson’s UK was it?***

**Answer:**

And I, I thought it was. The first meeting we went to there was the Parkinson’s UK Representative and she was wonderful. She sat down and she was talking to everyone. This leaflet, that leaflet; she was helping a lady trying to get a bed for her husband and I thought this was just incredible. So, it was, I think it was an invaluable thing.

**Interviewer:**

***And what sort of information did they talk about?***

**Answer:**

Well, um, sort of what grants you can get; what

**Husband:**

Benefits, grants

**Answer:**

Yeah, um, if you’re finding your medication is not that good, suggesting that person or that person, it was just general basic things, but it was absolutely brilliant. I would, I really would recommend if all of us could do that it would be wonderful.

**Interviewer:**

***And you get the Parkinson’s UK magazine***

**Answer:**

Yes, we do. That’s the one with the (giggle)

**Interviewer:**

***How do you find the information on there?***

**Answer:**

Quite often you look at it and you think, ‘oh’, there’s a lot of it and it’s almost, for you, it’s almost too much. He does the headline bits. But then sometimes I’ll get into one and read it and I’ll think ‘wow’. You know, there was a lady the other day that gave up work, instead of working in a room on her own and leaving her husband around the house with Parkinson’s all day she retired. And now, it’s a much calmer; she can chill out; he’s a lot more chilled cos he’s not waiting for her to come out at dinner time this sort of thing. And I thought, yeah, you know, it’s hard looking after somebody with Parkinson’s because, like I say, he is changing. And I find it quite funny cos if he leaves something now I put it on his chair and then he puts it in the bin. (giggle)

**Husband:**

I was going to do that.

**Interviewer:**

***And I suppose how you found, you know, supporting, caring for (husband)? Has that changed over the last few years?***

**Answer:**

No. the only thing that has changed is, um, again through somebody at the Parkinson’s said that her husband no longer did the finances. Um, and I didn’t go into asking why, but obviously something had gone wrong and I am a little bit more aware of that now. For example, when (husband) does the shopping, the food shopping, he says ‘how many jacket potatoes do you want’. I said ‘eight, no did I’

**Husband:**

No, four.

**Answer:**

Four, I said ‘four’. So, he got

**Answer 2:**

Cos there’s 4 in a pack

**Answer:**

Yes, so he got, how many did you get?

**Husband:**

I got 4 packs

Answer:

4 packs. (giggle) You know, and then what happened. Oh, there was some prawns, and what happened with those, they came raw and I don’t like raw prawns. It was (giggle)

**Husband:**

And tinned, ordered some tins of soup and they were the wrong ones.

**Answer:**

Oh yes, there’s a curry one we’ll have that.

**Husband:**

I bought in red tins.

Answer:

But his generalisation I would say

**Husband:**

Just tell them the ..

**Answer:**

I would say now if we were doing a large transaction or something, um, and also I like him to tell me what he’s doing on the internet. Um, because one of the things that I noticed on Y he ordered some pills, just cod liver oil pills. Now he’s never, he never does anything unless we talk about it and I thought that was really strange cos I said, ‘what did you do’ and he said, ‘I ordered them’. ‘what’, and I couldn’t believe it. It was like he didn’t need to tell me; he just went and did it on his own. So, I’m a little bit more wary now, of that, I must be honest. I am, but then I make mistakes, you know. If I’m counting £500 quite often he’ll be better than I am. So, it’s, its

**Husband:**

I did book two nights in a Premier Inn

**Answer:**

Oh god, yeah.

**Husband:**

It was supposed to be one night.

**Answer:**

I got there, remember, and she said, ‘oh, that’s funny there’s two (husband)’. Well I didn’t think anything of it. And then when we went, we came home, and we looked on the bank statement you’d pay for 2 nights instead of 1.

**Husband:**

I must have pressed twice.

**Answer:**

But they gave it back to us, they were so sweet. (giggle)

**Interviewer:**

***And what about yourself. Do you have any medical conditions that you.?***

**Answer:**

Oh, God yeah. Yeah, I’m not great at all. Yeah, I can’t bend down so my knees are shot and I’ve got very bad hips. They think it’s the nerve running from the back of the spine going round into the groin. I get a lot of stabbing in the groin. Um, a lot of hip problems so I’m absolutely useless really, I can’t do a lot of anything. (husband) does an awful lot of, I can’t get down on my knees at all. Um, so we just work with each other, you know. If I can’t do something he does it and if he can’t do it I do it.

**Husband:**

And now we’re starting the problem with I’m becoming less capable. I’m not fit enough.

**Answer:**

And there is another thing as well

**Husband:**

If I get down I can’t get up.

**Answer:**

There is one thing I’ve noticed as well. (husband) and I are quite meticulous about what we do cleaning wise and everything like that. and I’ve noticed that he’s actually getting tired, and I’m getting tired. I would have had a cleaner in here now, months ago, but I’m frightened because of Covid. I don’t know what to do. Do we just struggle on for now which I think we’ll probably going to have to because I think ‘where does that cleaner go?’ Does she, how many houses does she visit? I’m quite scared so, it is that, but we are getting to that stage I must admit. We are getting to the point we might have to have someone in because, (husband) finds doing the bathroom, he gets quite tired and so do I, but that’s, the Covid thing as well, you know, it’s difficult.

**Interviewer:**

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

**Answer:**

Yeah I do. I have high blood pressure, um, and I have a lot of err, constipation cos I had major surgery on my stomach. Quite a few operations, about 7 now. And um, where they’ve redone everything I don’t go to the toilet very well, so I have to take medication for that. Um, and then occasional painkillers when this gets really bad. Um, yeah

**Interviewer:**

***How many medications do you take?***

**Answer:**

I take, um, a laxative for my bowels; I take my Ramipril for my high blood pressure and eye drops; I have dry eyes and that’s it really.

**Interviewer:**

***And do you find, how has it been, how’s it been looking after your own health while helping (husband) with his Parkinson’s. do you think that’s had any impact?***

**Answer:**

No, not really. I just think my main concern is that I, now I notice that (husband). Actually (husband’s) become a bit like me. I, before (daughter) passed away I was okay. For the first year I was alright, but the second year I wasn’t so clever. And now, I’m worse than I was in the beginning. So, I get very anxious about things. Like he was saying that he really likes to do his decorating and he was getting on really well. But he was, but he was doing it till 4 o’clock in the afternoon and I was exhausted, absolut, I know he wanted to get it finished. Cos you imagine doing in the hallway you can’t get past each other, it was just, agh. It was awful. So, I could see his point of view but, it, I, I was getting tired. I’m getting tired now at the end of the day and, we’re doing these little sort of stops now aren’t we about 11 o’clock. Have a coffee and read for half an hour, and that’s what we’re, and we do one in the afternoon sometimes. Um, and that’s helped a lot. I have to say, isn’t it, it’s been quite good. (husband) will sit down and do a little puzzle or sudoku or something and so that’s good, but yeah, its. I don’t think his Parkinson’s has made it much different apart from when I have to do a few little things for him. He’s quite funny really what he does. All the drawers and the cupboards and stuff, it’s great.

**Interviewer:**

***And thinking about (husband’s) Parkinson’s. Are there aspects of looking after his Parkinson’s that you find difficult or challenging? From your point of view***

**Answer:**

Um, there’s only one thing I would say, and that was that um, sometimes he’ll definitely say that he hasn’t done that, and I know he has. But he won’t admit it. So, between us I don’t notice anything, but other than that no. that is something I have noticed, he will occasionally say, ‘I didn’t do that’ and I say, ‘I’m afraid you did’. (giggles)

**Interviewer:**

***And do you monitor his health?***

**Answer:**

Yes, I watch a lot of what he does. I shouldn’t say it cos he’s not meant to know (giggles)

**Husband:**

Yeah, all the time.

**Answer:**

I do watch him. Um, yeah I do. And I’m very aware of his walking; my walking’s terrible. I notice he is definitely without any question of a doubt tripping more. Um, we had an OT come the other day, and err, she wanted to err, she said about putting a step in front of cos we have a step that much to get into the shower. But when you put the step in, the bathroom’s so small, you would have tripped over the step in order to, so it just wasn’t working. So, we’re looking, and I don’t know if it’s possible, but they said something about, for later on perhaps, he might be able to have a wet room where it’s all on the flat for him. And the toilet’s far too low; for both myself and for (husband), but for for (husband). Um, it’s a very, very low cistern so they’re going to try and put one higher. I think we might have to go through hoops and stuff to get it but at the end of the day, we’re, the family are supporting us financially to get a door in here. Because, (husband) as an individual is quite a quiet private person. All these people chatting on in here, it’s great, it’s lovely but we are quite private. And I know, and he has said to me on many occasions, he won’t go out that door, round there, all the way round there and open the gate. Just to sit in a chair. Now, if I wasn’t here, and the children were, you know, different parts of the country I would like to think that if that door was in he would open it and go and sit quietly and read his book or whatever he wants to do. Um, so that to me is very important. Um, and its hard to explain and that cos people might just think, oh cos we’ve got a garden its not the case its more for, if I wasn’t here or later on if he gets more disabled I know he would be more likely to go through that door than you would be. He probably just wouldn’t go out.

**Interviewer:**

***And how did you get access to this OT?***

**Answer:**

Um, she came through the Doctor, the Consultant. Um, *(PD Specialist)* yeah, that was it, yeah, that’s right so that’s really good. In fact, I am actually thinking I need to see someone because I’m so much worse than I was, but I’ve got to work that out how I get to see an OT. But, um, yeah, I think also it’s important that I look after myself because, if I get any worse I just won’t be able to do the things I need to do for (husband). It’s a balancing act isn’t it really. you’re trying to keep both of us going at the same time.

**Interviewer:**

***And you talked about jumping through some hoops to get, you know, what sort of hoops do you envisage?***

**Answer:**

I don’t know how it’s gonna work. What it is we have an Area Manager, apparently, connected to this place. I’d never met her until Friday, Wednesday sorry. Um, now she comes out and nobody sees her very often but when she comes here, whoever’s got a problem she comes to see them. So, she came into see us to measure up the windows to see if it was possible, and then she said. I said to her, ‘oh by the way (husband’s) had an OT come and see us to get, possibly get the toilet seat, the toilet raised’. And she said, ‘don’t worry I think we can do that for you’. And I said ‘also, it’s a little bit concerning that he’s tripping getting into the shower’. It’s a silly shower, it’s that deep. Why for an older person you wouldn’t have it, but anyhow that’s the way it’s been done. So, she said, there’s a thing called, what is it?

**Husband:**

DFG

**Answer:**

DFG which is, basically you apply for a grant. We didn’t even know it existed. And that’s what she wants us to do. Not for the door, cos she appreciates that we will pay for that, um, but this is for a wet room to be put in. Whether that happens, but going through hoops, what I’m basically saying it could take months.

**Interviewer:**

***And is that the lady from the Housing Association?***

**Answer:**

Yes it is. It’s the Area, Area Manager I think.

**Husband:**

They require all sorts. Specifications

**Answer:**

She has said, oh yeah, of Covid.

**Husband:**

Right from costings, each step of the project. They require insurance of £10million. They want so many things from these things whatever

**Answer:**

It’s been going on for months. And that’s another thing I would say, as well, both of us have been so anxious about this because we can’t order furniture; we can’t put the flooring down; so, have had to leave it at the door. We’re sitting in limbo, and you know I think, well can’t you just say yes or no? I don’t mind either way, you know. We’re having proper people come in, you know, really good firms, it’s costing quite a lot of money, but the children are going to help us. And I just think can’t they just make their minds up just one way or the

**Husband:**

We applied on April 4th and we’re still sitting here waiting.

**Interviewer:**

***So, they need to approve the door?***

**Answer:**

And also we found out the other day, I didn’t want to hide it from everybody cos I didn’t want them to think we were special p people or anything, but I mentioned to a few people that we had applied. The lady that lived here before, she wanted one in, but she wanted it right across there, well they turned her down obviously, and so I did mention it to a couple of people. The lady next door is quite disabled, now she wants one. So, when the Manager came in she said it’s got to be feasible for everybody. And I said I fully understand that. But, you know, it’s just about

**Husband:**

Because it’s taking so long the quotes and the insurances have

**Answer:**

Oh yeah it’s all run out.

**Husband:**

Gotta get new ones to send back and you think ah

**Interviewer:**

***Um, I suppose, and err, we talked about (husband’s) hospital appointments. Do you always go to his appointments?***

**Answer:**

Yes, always. Yeah

**Interviewer:**

***How have you found that?***

**Answer:**

Fine. Um, I don’t mind going to them. I think that worst thing was the meeting we had where they stuck names on ya. I just said to him at the time, ’I’m gonna have to leave in a minute I can’t cope with this’.

**Husband:**

It does help

**Answer:**

Does it? Well I suppose it does.

**Husband:**

Well we both went to the exercise class. We had name tags. That’s a week or two, we got to know everyone.

**Answer:**

I just found it very patronising.

**Husband:**

Then you get rid of them. But initially its quite good. I can’t remember names.

**Answer:**

I suppose I didn’t really want to be there did I. sorry, nor can I.

**Husband:**

Been here 6 months and I don’t know half the people in here

**Answer:**

Well I don’t. and the garden lady or so and so or whatever. But its

**Husband:**

The one with the garden, yeah.

**Answer:**

I found it a little bit difficult the first meeting I went to, but I don’t think it was a particularly good one. Had I been to what I call more organised and better, actually we just sat there horrified at these poor people that weren’t speaking, and it was awful to watch. Um, and it was, it was quite frightening as well being a first-time person to go, it just, I don’t know, it just didn’t seem right. But as I say when we went to *(previous city name)* that was a very different, different kettle of fish.

**Interviewer:**

***And what about the experiences of Healthcare Professionals and your appointments there with various Doctors?***

**Answer:**

I don’t think the, I don’t think there’s a lot of consideration for, for Parkinson’s people. I, I for anyone suffering, for the only thing they don’t want is disruption. You know, (husband) doesn’t want to be seeing the Doctor on the 7th June, and then find out he not seeing him till the 2nd of August and then it gets changed again which frequently happens. And I just feel that perhaps they should think a little bit more that that sort of thing can really jolt people. It can get them quite stressed out. I mean he isn’t too bad because I’m always there and I’ll say, ‘oh don’t worry, that’s fine. That gives you chance to do something else’. But for a lot of people, I think, especially if they’re on their own, I think that could be quite

**Husband:**

And I just think about when we lived in *(previous city name)*, (wife) was due to have a needle into the hip (oh yeah) which had to be done under theatre conditions. Since we come here because of that break and moving

**Answer:**

I’ve not been able to see anybody.

**Husband:**

Should have had it done by now, but

**Answer:**

They should have contacted me via my other Doctor, but I haven’t

**Husband:**

They should have arranged to have it done here.

**Answer:**

They should have really dealt with it, but they haven’t.

**Husband:**

And so, it’s left.

**Answer:**

and because I’m too frightened to go to the Doctors, because of him, I don’t want him. And I must admit I did go to the Hospital last week because they thought I might have mouth cancer. Um, I haven’t, so the Consultant said but, what was concerning I went into Poole and I was told that it was all separated and it was this and it was that. Well it was a nightmare. I was in there and it was like this; doctors, nurses, everybody close together it was awful. And I, it was absolutely, and today I went for my Mammogram in the Unit at (hospital) and again I was told there would be one nurse; one receptionist; one patient in a time. When I came out of the door, even before I’d gone in there, there was 6 in there and I felt it’s not good, it really isn’t. I mean I know they’ve got to rush people through but, we are in a pandemic, and it’s getting worse.

**Husband:**

And there’s not the continuity of care is there

**Answer:**

No there isn’t. that’s another thing.

**Husband:**

You gotta start again. Start from the bottom

**Answer:**

Its like you’ve just got Parkinson’s sort of thing.

**Husband:**

It took 2 years to get to that stage.

**Answer:**

Yeah 2 years for me to be recognised that I need an injection and then they found out that it was coming from the hip. Um, so yeah, it isn’t good. But then, then I, I have the attitude that, I haven’t got cancer. So, you know, at the end, and look at (husband), you know, he’s not bad. You know, there’s somebody out there being told today and that really gets me. I think it’s so important that we recognise that he’s, he’s got a really good life I think. Ya have to deal with things I know, but overall, you’re quite lucky aren’t you

**Husband:**

Everybody gets something.

**Answer:**

Well yeah, I mean someone today will be told they have got cancer wont they? And I think that’s more a thing if you like.

**Interviewer:**

***And, have you ever, if you ever, if you do have a question about Parkinson’s or anything, what would you do about that?***

**Answer:**

If I, sorry

**Interviewer:**

***If you had a concern about (husband’s) Parkinson’s from your point of view, or you had a question about Parkinson’s what would you do?***

**Answer:**

What me? I’d go straight to a Consultant. I don’t mess about, I’m straight on the phone. If I thought there was something wrong with him, I don’t hesitate, I’m quite straight forward.

**Interviewer:**

***And do you know how do access them if needed. Have you had to do it?***

**Answer:**

Yes, I do, I do. I would just get onto the one we had in the beginning in (*city name*). And I would just ask for an appointment and I would, yeah. I said to (husband) when we first found out that you got this, we, I said to him, the one thing you’ve got to do is trust me. If I tell you something, you have to believe me, you know. It’s no good saying, ‘I don’t do that, I don’t do that’, because, you know, we have to have trust between us. And sometimes I will say something, and I don’t think he really agrees, but he sort of, you know.

**Husband:**

Accept my symptoms.

**Answer:**

Yes, you don’t, and I think that’s a really good thing. It’s like that with the bank thing, you know. I did say to him double check things with me please. Um, and I don’t think he really wanted to at first, cos the answer was, ‘well I’m not that stupid’, you know, but in all honesty even I can make those mistakes without having Parkinson’s, but it is, it is a concern. You know, you press the wrong button and you could lose thousands couldn’t you, sort of thing. So, it’s, it’s just something. You’ve got to work as a team. Um, this lady I met in *(previous city name)*, when she said about having to take over the finances, you could see that she was a t a stage where (name) was doing the wrong things. Um, you know, whatever they maybe. So, and there is that aspect of Parkinson’s, you know, I think people that have got Parkinson’s sometimes think they’re doing something they’re doing it correct, but they’re actually not. So, there is that in it as well.

**Interviewer:**

***And how’s your experiences in trying to get help for your Parkinson’s or (husband’s) Parkinson’s?***

**Answer:**

Um, not a problem. Like I say, I don’t mess about. I just pick up the phone and whoever I need to speak to. If I couldn’t get to see a Consultant then I would probably pay privately, just to get my answers if I was really worried about him. Or I’d just say to him, ‘I think you need to go to the Doctors’. And we’d do that first wouldn’t we.

**Interviewer:**

***Go to your GP first you think?***

**Answer:**

Yes, I think GP first unless something, unless I notice something was really wrong. like you know if all of a sudden he was like a bit vague, and that sort of, I don’t think I would bother with a Doctor I would

**Husband:**

The only problem is because we’ve never actually been to the Surgery.

**Answer:**

No

**Husband:**

And we haven’t got the rapport with any particular Doctor.

**Answer:**

No. And we’ve always had that.

**Husband:**

We’ve always had that. Where they know our history, they know everything about us.

**Answer:**

I mean our last Doctors in *(previous city name)* actually said he was really sorry we were going. He said you’ve been al lovely couple and it’s been a pleasure to know you. And I thought isn’t that nice. Yes so,

**Husband:**

We don’t even know their faces here.

**Answer:**

No, we have no idea.

**Husband:**

Cos we haven’t been. (giggle)

**Answer:**

No, but again, tell a lie I did go, didn’t I the other week cos they had to look at my face, just inside my mouth and that. And I went, that’s the first time. I went in there for about 25 minutes; there wasn’t a single window open and it was unthinkable. Why can’t you just open the windows? I mean what do they say, fresh air, ventilate. And there was nothing. I said to you when I came out, it was awful. But I don’t know.

**Interviewer:**

***What have been your experiences, we talked about the care co-ordination for Parkinson’s. What’s your thoughts about that? (husband) talked about it***

**Answer:**

It’s fine at the moment. I think it’s gonna definitely increase and I think, I’ll probably get worn out I would think like most people that look after somebody. Cos I think it does, I, there will be time. All I can go on is what people have told me, and it does get tiring. I mean (name’s) wife for example, (name) can’t speak much now. Um, and there’s so much, like she would say (name) I’m going to go in the garden and do some work and she said to me one day, she said, ‘you know, he doesn’t’. I said, ‘what does he do then?’ She said he goes and sits on the bench and falls asleep. For (name) he’s doing lots of things in the garden.

**Husband:**

That’s another thing with Parkinson’s. you get to a point where; you can’t join a conversation. (yes) So you tend to stand back, and then you both become more isolated, because we used to say to (name) ‘how you been today’ and he said ‘err’ and then his wife would step in and tell us what he’s been doing. So, he didn’t bother in the end.

Answer:

And that was so sad. From outsiders we could see that. (name) thought she was doing the right thing to save him having to try and force himself to speak. Now there was another chap there, who was a friend of (name) for about 7 years and he knew exactly what (name) was saying without having, you know, to do that. But, yeah, I think we said this about your dad. When his father got older and he got deaf, we noticed he stepped back a lot from conversations with groups of family because he couldn’t hear. And it’s a similar thing isn’t it. Very similar thing.

**Interviewer:**

***Um, obviously (husband) doesn’t have care at the moment and you help him. Have you, do you have any information about what you would do if, you know, things were to get worse and you were to need help. Are you***

**Answer:**

I think I would probably speak to a Parkinson’s person regarding what is best to do. I mean if you take everything away from somebody that leaves them with nothing. So there are certainly things I would him to carry on doing, but I think the most important, as my Arthritis gets worse in my knees and hips sadly, I realise I am not going to be able to do certain things. I can’t do the bottoms of the, you know, the kitchen doors and things I can’t bend over very much. So, I think it would just be a cleaner and we’d muddle through the rest of it together. Um,

**Husband:**

We get some laundry done.

**Answer:**

Oh yeah I get my laundry done now. Err, which is great.

**Husband:**

Cos that’s too much

**Answer:**

That relieves that of me, so I don’t have to keep going down to the Laundry Room and stuff like that, so that’s good. But I do think it will be that. it will be having to put things in place. The terrible thing is at the moment, um, I think we’re there now wanting a cleaner just to do a couple of bits. Like doing inside the shower and that, you know, I can’t bend; it’s quite small; he gets a bit, you know. But I’m so, I’m not sure about having someone in.

**Interviewer:**

***Cos of Covid***

**Answer:**

Yeah, and once that. I suppose eventually I might have to, you know, but I think we’ll have to, I think we’ll play it by ear, yeah, and see how we get on. Um, we’re not very rich so we can’t have a lot of people in. We’ll just have to judge which is the best thing to do, you know, at the time really and weigh it up do you think.

**Husband:**

Yeah, get the major things done.

**Answer:**

Yeah. the biggest things done and then

**Husband:**

Potter round the rest.

**Answer:**

Then, we can manage that. We change the beds together and things like that. That was something we did a couple of years ago. We had to change our beds and we went for singles, because (husband) does do a lot of this with his hand. And I felt well, it’s alright now, but then do we want the expense of another lot of beds later on so we decided we should do that didn’t we.

**Husband:**

We used to clean the car regularly, every week, without fail. We don’t do that now. (name) puts it through the car wash.

**Answer:**

And then

**Husband:**

It’s an expense but

**Answer:**

And then what I call luxuries if you like. Things like before where we would

**Husband:**

Such an effort

**Answer:**

We would be out every minute, we’re both a bit tired I think.

**Interviewer:**

***And do you help him with his medication?***

**Answer:**

Yes, I do, yes in the morning. I lay it all out, out the front here and we have two little pots and he has his and I have mine. Um, and that’s it. And then we’ve been talking recently about the bathroom as well. I think there’s going to come a time, when there’s a nice shelf to the sink and I’m thinking right, whatever he does now I think I will do that for him, in his routine, and that will be how that goes I think at the moment.

**Interviewer:**

***So, his medications?***

**Answer:**

Yeah, and the same sort of thing. I mean sometimes he will come out of the bathroom and he doesn’t quite know what he’s up to. And then he’ll say I’m alright now and go back in again. But, yeah, I think that is what’ll happen. It’ll be like sort of – you know when someone gets old and they, they sort of need a bit of help dressing and stuff like that, I think that’s all going to come. Um, I’m not sure how I’m going to cope with it, nobody knows do they, really, but

**Husband:**

I can’t do up laces or anything. Sometimes fumble the buttons, can’t do the buttons.

**Answer:**

You’ve been amazing when I’ve been ill. When I’ve had major surgery, he’s done everything for me, and to me, I’ll do the same for him. Um, you know, if we can.

**Interviewer:**

***Yeah, yeah and if you were to get to a point that you need help like Carers, are you aware of where to get information like that?***

**Answer:**

Err, um, I think so, yeah. I probably would, I think I’d probably go to Social Services or to his OT. That

**Husband:**

She did leave a leaflet actually.

**Answer:**

Did she? Oh alright, okay. I, I do

**Husband:**

It’s in the cupboards.

**Answer:**

I do think, um, that’s probably where I’d start off. I, I think, to be honest with you, because we’ve always paid for things ourselves, we haven’t asked for anything. Like, there are some people in here wanting the door, but they want to get it through Council and all that sort of thing, I think because we’ve always done that, never really asked for anything, we don’t know about these things. But I do think that people like OTs and House Managers, they are very knowledgeable.

**Husband:**

Also, the Parkinson’s Group

**Answer:**

Oh yeah, the Parkinson’s Group that’s another thing.

**Husband:**

They’re really helpful. Cos they’ve been through it; they know who to contact and could give you names and phone numbers.

**Answer:**

I mean basically it could come down to needing Parkinson’s Carers. As, the same with the Cancer Carer. You know they’re specialised in that, and it could come down to that. the only thing I would never want, I would never want (husband) to go into a Home unless, you know, it was absolutely, but I don’t think that’s going to happen. I think we’ll manage and if I can’t manage I’ll bring people in to do. And the kids are around, they would come and help if necessary so, um, so I think

**Husband:**

Don’t have to worry about for a long time.

**Answer:**

No, we don’t want to.

**Husband:**

… obligate them.

**Answer:**

I did say that to (name) actually when we got back, cos they just bought a house, a bigger one. And I said to, you know, ‘anytime you feel you want to sell and go off and do whatever you imaged you want to do, then please do. Don’t feel because we’ve come back, you know, all of a sudden you’ve got to look after us’. And she said, ‘no mum, I won’t, don’t worry’. (giggle) so I think we’ll be alright.

**Interviewer:**

***And then again from your point of view, how do you think the Healthcare System can be changed to try and help you manage, you know, someone with Parkinson’s now that (husband) – from your point of view as a caregiver?***

**Answer:**

I think there needs to be a, just a bit more talking to people. A bit more connection with things, you know. Like, if you happen to get a good Nurse, then that’s fine, but if you get a bad one nobody knows anything. Like I say, when (name) first got his Parkinson’s, ‘it was yes (name) you’ve got Parkinson’s’. And, there was nothing, you know, there really wasn’t anything. And, cos I said to you at the time, I find that quite amazing in this day and age. Um, see, I don’t know really what would have happened had we have seen a Consultant through the system, as to going privately, I don’t know if that would be any different. But apparently this Consultant does do, um, NHS work as well as his own private work. So, probably would have got the same sort of service, but I do think it can be improved. There’s a little bit of dotting up to be done, generally. Um, if you’re really, if you’re a really quiet person that doesn’t really say much, or do much, I think that might be quite hard. I certainly think if (husband) was on his own, and he found out he got Parkinson’s, I don’t know if he would have done the things that we have done cos I’m more up there. I’m sort of, although I don’t like going to meetings very much, to be honest, um, I just think, I don’t know if you’d have done some. I don’t know if you’d have gone to the gym to be honest. I just don’t know. So, if you’ve got a person with Parkinson’s that’s quite reserved and quite quiet, I think it would be quite hard to get help. Because, you know, unless you’re prepared to ask, you know, it’s

**Husband:**

It doesn’t come willingly.

**Answer:**

No, it doesn’t, it doesn’t really

**Husband:**

You have to question and answer them.

**Answer:**

Yeah, you do. It’s like the pills, they’re very quick to want to. That’s another thing I find, they’re very quick to want to get you onto this, and then onto that, and then onto that. and from my experience with the people I know from Kingsbridge, all three of them are not doing very well, which is quite sad. And its, when I spoke to her the other day, she said, ‘well it’s the medicine, they haven’t quite got it right’. And then the other one, um, the other lady that had it, she was not doing her medicines correctly and she was. Basically, she was taking them when she thought she’d take them. Now with these medications they’re like, as (name) always says to me, ‘its 12 o’clock you take your medication; 4 o’clock you take your medication. Now, some people aren’t going to do that, or forget, so I sometimes think is it. Are these medicines as good? It depends on the individual they need them really. Um

**Interviewer:**

***And how have you found (husband’s) Parkinson’s medications. He only takes Selegiline, how have you found that?***

**Answer:**

Okay. Um, I think, I think I have to leave that judgement to him. For him to decide

**Husband:**

..because I’ve been taking it so long, I couldn’t even tell you what it would be like not to take it. I don’t know what I’d be like. I don’t know if it’s working or not.

**Answer:**

It’s like sleeping pills. If you take them long enough they don’t work, you know, any Doctor will tell you that. so, I don’t know. What would you say today, would you say that they?

**Interviewer:**

***It’s obviously difficult for me to comment without your history and your symptoms um***

**Answer:**

It would be interesting to know if it’s actually doing any good anymore (giggle)

**Husband:**

Well there’s nothing that’s going to cure it.

**Answer:**

No, no there’s not

**Husband:**

It might help with the symptoms, but that’s as much as you can hope for.

**Answer:**

One thing I have noticed about (husband), in his deterioration is, is. I might be saying, ‘alright I’m just going to put the rubbish out’, and he’ll say ‘yeah, I’m not ready yet, I’m not ready yet’. He needs to get his phone and his keys and I’m a little bit impatient in that. I have to learn to be a bit slower because I don’t, I’m up the road and I’m doing things before (husband’s) sort of getting to the door (giggle), which is basically difficult.

**Husband:**

I have a system.

**Answer:**

Yeah he has a system. And sort of

**Husband:**

I have to use the system

**Answer:**

And I’m, I’m already gone. So that’s something I have to learn. But I have noticed a vagueness there. Very much like the day I said when he was walking down that lane, it’s sort of like, I thought to myself, ‘are you with us or are you somewhere else?’ And I’m noticing that more. Um, and I don’t know

**Husband:**

Well my mother was like that as well.

**Answer:**

Was she?

**Husband:**

That vagueness.

**Answer:**

Was she

**Husband:**

When you chatted to her for a while she just went

**Answer:**

Oh yes, but I just think that was because she had

**Husband:**

She had Alzheimer’s

**Answer:**

She had a very low span. You know, you’d be talking to her and if she wasn’t interested. They did a test on her. The Nurses came round to do an Alzheimer’s Test. And they did three things and she said, she told me afterwards. When I got to the fourth they could tell (name) wasn’t interested, she’d .. I’m looking out the window at the neighbour or something. So yeah, I think that’s part of it.

**Interviewer:**

***Could be, yeah. it’s difficult to know***

**Answer:**

Yeah, cos there is that little bit of vagueness, um so yeah. I think the biggest thing of all that we can do is, is more talking with Parkinson people; with their families; with their Carers. I think it’s invaluable, absolutely invaluable. I think, I think it’s something for every problem isn’t it, whether its cancer, Parkinson’s, Alzheimer’s whatever. People need, I think if there was anything at all, it would be great if there was more availability of meetings, whether it be the Hospital or wherever it be. No, I think it would help the Carers, so much more. Err, some people will need it more than others. I don’t particularly need it, but I know there’s some people that thrive on it and are so much better as a Carer by going to these things because they can share it. Um, and I think that’s one of the biggest things. And a little bit more from the Doctors maybe. Cos there is very little, you know. You just get a letter and you’re sent away and, ‘don’t worry (husband) I’ll get you sorted, you know. And that’s it. And you sort of think, ‘aw’. It was a bit daunting wasn’t it?

**Husband:**

Yeah. its, I think if you’ve got a meeting of minds, you feel better. You aren’t any better, physically, but you feel better about yourself.

**Answer:**

There were some people that went to this meeting, once a month it was. And it was in a pub and you had a meal. Some people didn’t, they just had a sandwich or whatever; not everyone drunk, you know, it was just whatever you wanted to do. And there was a man that used to go there, and he lived on his own, and he had Parkinson’s and he was getting slow. But do you know what, he enjoyed that so much, and he happened to get in with a couple of ladies that were a bit like that as well, and he used to sit next to them and you used to hear them talk. It was so nice.

**Husband:**

It became quite a social event. You were supposed

**Answer:**

Yeah, because they were learning things from each other. And I thought that was wonderful.

**Husband:**

Whereas if you’ve got Parkinson’s and you go to a normal social event, you tend to be on the periphery. You stand back, but because you’ve all got Parkinson’s you socialise with people. It’s like minds.

**Answer:**

I think it’s invaluable, that

**Husband:**

Quite …, it does help.

**Interviewer:**

***I suppose is there anything else, as a Carer of someone with Parkinson’s, that you do that we haven’t already talked about. We talked about some of the symptoms, and ..***

**Answer:**

I think Carers need to be aware of the things that you are not aware of at the beginning. For example, the worry about money. You don’t see that person as someone, (husband) is very meticulous is what he does. He’s always done the banks, he’s always done everything, he does now to a degree. But I never thought he would do the silly things. Um, if you don’t mind me saying, some time ago he bought something and then all of a sudden we had people phoning us up and err, I said to him, oh dear, there’s something really bad here. I said you’d better, so we went straight to the bank and got the card changed and everything. And I was quite firm, and I said, ‘don’t ever do that again. You must tell me’. That is something he would never have done, but no-one told me that. apart from my friend saying that, you know, she’d had to take over the. So, there are things that are quite important, cos that’s a serious thing. You know, people could lose their life savings and things, so I think. Maybe there should be a booklet or something, you know. Be aware of this; be aware of that.

**Husband:**

Then if you’re meeting socially with people with the same

**Answer:**

You find this all out, so again, to me the most invaluable thing is an OT with some specialists coming in. And also, that was another thing they did, they taught (husband) how to fall and roll, and I, you don’t think about those things do you really.

**Husband:**

Fall..

**Answer:**

The guy showed him how to turn and we were all there at this meeting. And it was absolutely wonderful. Because you don’t know how to fall, no-one does really do you?

**Husband:**

There is a way to fall.

**Answer:**

Well there is, and, you, you’re very aware of that now.

**Husband:**

Yeah, yeah

**Answer:**

I mean I had a nasty fall in (city) some years ago. I caught my foot on a pavement and I went smack. And I must admit I don’t know what happened to insides, but I felt so ill for 3 weeks. And it was strange, cos we’re always together normally and I’d gone in on my own. So, I was in a real bad way coming home. Now if I’d have known what that man had told me, as I went I would have known to turn and roll, but I didn’t know that. so, I think that all these little things make a big difference to somebody’s life. Um, it’s like knowing how to use crutches, you know. It’s not that easy, some people can do it, some people can’t. I think its information really isn’t it, in a lot of ways and a little bit more from the Doctors I think. Maybe they should have a Nurse Practitioner that has an insight into Parkinson’s, and if she hasn’t got time to listen to it all maybe just give a leaflet, a beginner’s leaflet. And then, in that leaflet it could be – join the Parkinson’s Group, so you do find out lots more. Cos I think people feel isolated. Um,

**Husband:**

Cos you are left to do it on your own. Get in touch with these people, they don’t get in touch with you. You have to get in touch with them.

**Answer:**

Perhaps there should be like a link. You know, if 35 people go into *(local hospital)* and they’re diagnosed with Parkinson’s, perhaps that should be linked to the Parkinson’s so they can then send out, ‘hello, you know, we’re here’. ‘How can we help?’

**Husband:**

In the Group they used to send little text messages, e-mails and just little bits and pieces and you felt part of it. Not alone.

**Answer:**

And that’s the thing you see, as I say, if (husband) was on his own he’d be very different. Terribly different. So, it’s only me that I think that really projects that. And there must be lots of people like (husband) that won’t, you know, get, or not think it’s quite right for them. And you do get left behind, um, without a doubt. Um, I don’t know, its.

**Husband:**

You’ve got to deal with. But the mental things can be helped by association

**Answer:**

You see some, some, part, couples, don’t really work together. You know, I see a lot of it here. Husband does one thing; wife does something else. We do tend to work together and solve problems, where, as I say if you’ve wife’s been full on out there doing this and that, and you’ve got Parkinson’s, well it doesn’t help does it if there isn’t someone there to help you. Again, I think it’s a link up with all the things wherever possible. Do you hear that a lot?

**Interviewer:**

***Yeah, yeah, absolutely. Everybody’s experience are very different. It’s really interesting to listen to. No, it’s been really helpful listening to both of you obviously***

**Answer:**

Well I found that when I was at these things, you know. These people work far down the line to me, you know. Like the speech thing, I didn’t know about that; I didn’t know about the freezing, so it was really interesting. And it sort of, then you’re aware of it. So as a Parkinson’s person, you know, if something like that starts to happen, you think, ‘oh yeah (name) had that’, sort of thing

**Husband:**

Get it sorted.

**Answer:**

And it makes it easier to do. Otherwise you’d be thinking, ‘Christ what’s the matter with me?’ ‘What’s going on here?’ So, I think that’s another thing isn’t it. But, err, it’s been very interesting anyhow, really interesting.

**Interviewer:**

***That’s great, thank you***