# Interview P02\_ 240621

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| * Length of PD diagnosis – 3 years * x1 PD medications, three times a day + Statin * Lives with wife who is main carer (did not participate but was present at parts of interview and contributed her views too!) * Loss of son and daughter |

**Interviewer:**

***So, as I said we are mainly looking to try and understand your experiences about how you look after your health and what you have to do living with Parkinson’s.***

**But I thought I’d just start with some generic questions. Um, so how long have you had Parkinson’s?**

**Answer:**

It must be 3 years at least.

**Interviewer:**

***Okay, and you know, how did you get diagnosed?***

**Answer:**

My Doctor, when I saw him in (town 1), he felt there was something there, so he decided to get it checked. So that from Dr … (*okay).* And he didn’t, it just wasn’t good. He said to me ‘I think you might have it, but don’t take it until you confirm’. And that’s how it happened.

**Interviewer:**

***And did you notice any symptoms or?***

**Answer;**

I noticed, yes there was. I was a keen golfer and I had to give it up, because stability was a, I didn’t want to keep falling over. And one night I fell over, fallen and I banged my head (*oh dear, yes),* yeah. So that’s how it happened. And I went down to the hospital and I was analysed down there, and after about 6 to 8 months they confirmed I had it. And that when it all started with *(PD specialist)*.

**Interviewer:**

***And um, you know, how did you find out any information about Parkinson’s at that time?***

**Answer:**

*(PD specialist)* explained, and my son that died he did quite an analysis on it and fed a lot of information. So that’s how it was developed and, cos I hadn’t a clue what it was (giggle)

**Interviewer:**

***Yes, and how easy or difficult was it getting information about Parkinson’s?***

**Answer:**

It’s quite easy, it was very good. And (son name) did a bit of analysis as well.

**Wife:**

We had no information at all. And looked when (name) was diagnosed our son sent. We had a Fax Machine; he sent a couple of fax papers that he’d printed out. And we knew, I knew a little bit more but, we didn’t. the first signs of (name) having Parkinson’s, which we never knew, was his walking. He started walking round the garden, and he started pacing instead of walking. We noticed that he was pacing, and we knew there was something wrong, but we had no idea. We just thought it was another stage of being old, you know, (*yes of course*) and he stopped playing golf. But it was his pacing that did it, definitely, and you did that for about 6 or 7 months before you went to the Doctor. And the Doctor noticed the way he sat, and had to get up, and it was our Doctor. He’d gone down for a completely different reason, for his head, cos he’d hit

**Interviewer:**

**Hit his head, yes, so he said**

**Wife:**

His head, and that’s how we knew. It was the pacing. Literally, started to walk like Parkinson’s 6 months before he was diagnosed.

**Interviewer:**

***Okay, and how easy or difficult did you find, you know, understanding any information about Parkinson’s?***

**Answer;**

Oh good, I could understand quite well, I knew what was to come and the things that could go wrong and all that. so, there was a learning process.

**Interviewer:**

***Yes, yes of course. Yes, and how did you find that learning process?***

**Answer:**

It was good and obviously people are very helpful. There was a Nurse from *(City Hospital)* came a few times; did explain things like that.

**Interviewer:**

***Um, and was that helpful and?***

**Answer:**

Very helpful.

**Interviewer:**

***Okay, that’s good. And, what about, um, you know, starting medications as you do for Parkinson’s. How has that been?***

**Answer:**

Okay, good. Yeah, take the tablets every day, and that’s made no difference. Just keep on.

**Interviewer:**

***Yeah as in the medications haven’t made any difference you found.***

**Answer:**

Well, they might have done, not sure.

**Interviewer:**

***You’re not sure if they’ve made any medications, any difference?***

**Answer:**

I’m sure they have.

**Interviewer:**

***Okay, so obviously there, you’re showing me a little calendar that you have here. Is that what* *helps you, reminds you to take your medication?***

**Wife:**

Yeah.

**Answer:**

I make sure I do (do you)

**Wife:**

Three times a day.

**Interviewer:**

***So, you always take it down to make sure you do that?***

**Answer:**

Definitely, that’s right. (*and er*) That’s very helpful.

**Interviewer:**

***Okay, so just simple pen and paper.***

**Wife:**

But it’s easy to forget

**Interviewer:**

***Are there times that you have forgotten your medication?***

**Answer:**

No, No

**Wife:**

No

**Answer:**

I can say that with confidence. (giggle)

**Wife:**

Not with that.

**Interviewer:**

***And clearly you put quite a lot of importance in taking your medications.***

**Answer:**

Oh, yeah I think it’s important. Because that’s being said I must take it and I insist, I will say I’m taking that because it’s there for a purpose, and that’s obvious.

**Interviewer:**

***So even, do you think that the medications do help, or you are taking it?***

**Answer:**

I’m sure it does help it. Yeah, it does help it.

**Interviewer:**

***Yeah, okay. Are there times when you think it doesn’t?***

**Answer:**

No, not really. Because, I wouldn’t be taking it if it’s not necessary and I’m satisfied it is doing me good. And that’s how I look at it.

**Interviewer:**

***And do you find it easy or difficult taking your medications?***

**Answer:**

No problem

**Interviewer:**

***No problem, okay. And do you have any other medical conditions?***

**Answer:**

I take, err, couple of Statins for instance, and I’m at least taking this.

**Interviewer:**

***Any other health problems that you have?***

**Answer:**

No.

**Interviewer:**

***That you see your Doctor for?***

**Answer:**

No.

**Interviewer:**

***No, okay.***

**Answer:**

I haven’t seen him for a long time (giggle)

**Interviewer:**

***Yes, I suppose most appointments have been different and***

**Answer;**

Different, there’s no doubt about it.

**Interviewer:**

***Okay. And how have you found any of your appointments. Oh, let’s start with your Hospital appointments before Covid. Tell me how, what your experiences were of them?***

**Answer:**

Sorry I don’t understand.

**Interviewer:**

***So, before Covid happened (yeah), any of your Hospital appointments, for your Parkinson’s, how did you find, how did you find the appointments?***

**Answer;**

Very helpful. And they explained everything there was a question of. I .. around the Hospital and I found it very useful. Anything they were finding out about me; they were very clear; they explained it all.

**Interviewer:**

***Good. And was it easy or difficult getting to the hospital for appointments?***

**Answer:**

It’s not very nice to go down there apparently, because, I was worried I was going to go down and see you and that’s why I’m glad you came out to see me. I much prefer to go to *(City hospital);* apparently it’s much easier, and err, it’s just. I mean when you get there it’s easy, but err, car thing

**Wife:**

Disabled

**Interviewer:**

***So, once you get to the parking, you park, but I suppose it’s***

**Wife:**

You’re straight in.

**Interviewer:**

***Yeah. is that in (City Hospital)?***

**Answer:**

Yeah. And I like that. (*good, okay)*

**Wife:**

That’s the other thing (name) had, on his head.

**Interviewer:**

***It was …carcinoma***

**Wife:**

Yeah, there

**Interviewer:**

***Oh yes, sun exposure.***

**Wife:**

Yeah I think it is. But I just thought I’d show you that, yes, so that it was. Apart from that, well he’s finished now, and every 6 months but they said it’s okay. He had a biopsy done, yeah.

**Interviewer:**

***So, the issue was with parking. What was difficult about parking at, in which Hospital was this?***

**Answer:**

This is the

**Interviewer:**

***The (local hospital) one?***

**Answer:**

No, the *(local hospital)* is not a problem. (*okay*) The one in, err .. (*City hospital 2)*.

**Interviewer:**

**(*City hospital 2), okay. So, you’d prefer to go (City hospital 1) because of that?***

**Answer:**

Definitely, and when I had to go the Doctor advised me about my head, he had booked me into *(City hospital 2)*. And I said, ‘could you please change it; book me into *(City hospital 1)*’ and that’s what I did. So, it was a preference other than anything.

**Interviewer:**

***Yeah of course. Yeah, but it’s something that you think about in advance.***

**Answer;**

That’s right. Um, totally.

**Interviewer:**

***Yes, of course. And then how about your appointments for your Doctor at your Surgery, how have you found those?***

**Answer:**

Well I haven’t bothered much because I didn’t think I needed it.

**Interviewer:**

***Yeah, okay.***

**Answer:**

So, I haven’t been down to, to GP Surgery for 2 years I suppose.

**Wife:**

Yeah, well apart from jabs, yeah.

**Answer:**

Jabs, yeah there is that. I didn’t go into there to ….to a place in *(local town)* to have it.

**Wife:**

*(local town hall)*

**Answer:**

*(local town hall)*

**Interviewer.**

***Okay, for the vaccinations***

**Wife:**

Yeah

**Answer:**

And, sorry

**Interviewer:**

***And do you think there has been any difference in, you know, your appointments and, and going to see, I don’t know, any Healthcare Professional, before Covid and during Covid?***

**Answer;**

No

**Wife:**

No, we haven’t.

**Answer:**

Not much difference.

**Interviewer:**

***And just thinking about, you know, your Parkinson’s, what do you think the impact has been on your, on your lives or social networks?***

**Wife:**

Hundred percent.

**Answer:**

Hundred percent

**Wife:**

A hundred percent different.

**Answer:**

I also have a thing I, because I’ve been working, when I retired I got a job working , I set up a company, a holiday company and I’m still running that (*okay*) and I think I’m coming to the stage now where I should

**Wife:**

Retire

**Answer;**

Retire. It’s a company in Italy and I do all the,

**Wife:**

With his sister-in-law, he’s a partner. But she couldn’t do it without his head work, cos the mathematics, you know. And it’s, it’s trying now; very trying now for him to

**Answer:**

I’d love to do it.

**Interviewer:**

***In what way, you know, you clearly, you continue working all these years. In what sense do you feel that it’s***

**Answer:**

The reason that I’m getting new bits would, they’re not very good over there at sending all the information out to give the analysis. They send it and it’s not very clear and sometimes it’s not very accurate.

**Wife:**

Then it wasn’t a full-time job, it’s I’d say 30 hours a month kind of thing, it wasn’t a full-time job was it?

**Answer:**

But, it’s over there because they’re suffering, as you can imagine, in Italy with all the problems with

**Wife:**

And he started that about twenty odd years ago.

**Answer:**

When I retired

**Wife:**

Because he’s very active.

**Answer:**

They came over here, they spent about 2 months trying to convince me to set a Company, and that’s what I did. And I think I’ve done it, think it’s time I gave it up. I think 27 years is quite a long time to be a …

**Wife:**

Of course, yeah

**Interviewer:**

**And what impact do you think the Parkinson’s has had on that specifically?**

**Wife:**

Tired. He gets tired quickly.

**Answer:**

That’s in the morning .. cos, otherwise, yeah and find my driving is alright. I still do that.

**Wife:**

We don’t do motorway driving and a 5-mile radius now.

**Answer:**

I try to keep it

**Wife:**

A Circle.

**Answer:**

But err, I don’t have any problems.

**Wife:**

And I feel quite safe with him in the car. He drove yesterday,

**Answer:**

She always.. me (giggle)

**Wife:**

He drove yesterday to *(local area)* and back, which was the Garden Centre, that’s all. But we don’t do motorway driving or anything so just keep

**Answer:**

Can’t go far.

**Wife:**

A couple of times a week, really cos I go to the local shop. He tries to keep his hand in most things, and he walks every day.

**Answer:**

Yeah.

**Wife:**

His, but we’ve now invested in a, a walker with a little seat on it and he’s only had that for 3 weeks, and

**Answer:**

3 weeks

**Wife:**

And he’s really

**Answer:**

I really like it

**Wife:**

And he really likes that because he’s, he’s even, as opposed to the walking stick.

**Answer;**

The walking stick, because if it’s even near here, can’t bear it.

**Wife:**

Yeah, he’s not very good if the pavements are not.

**Interviewer:**

***So, you walk every day***

**Answer:**

…

**Wife:**

Tries, yeah.

**Interviewer:**

***Is there something that, you know, motivates you or, what, or do you set something you thought would be a good thing to do yourself?***

**Answer:**

I like to do it because I always like walking in the country, walking out and whenever

**Wife:**

And once a week you went to exercises but you stopped.

**Interviewer:**

***Okay, what exercises were they?***

**Answer:**

The down

**Wife:**

Village Hall for an hour a week. But the chairs, he’s now, he needs this to get up and down, you know, the chairs, so he stopped going. She’s just started again 3 weeks ago, and he just stopped going. But he does his exercises every day here

**Answer:**

But it did chairs they wouldn’t

**Wife:**

He’s frightened he’ll slip and, you know, (of course)

**Answer:**

And she agreed with me. Because she didn’t like the chairs.

**Wife:**

Is that (name), the lady who did them

**Answer:**

But, um, we weren’t there first, we had it in a different place and then when this, had to change, had to go to a different place and the floor was slippy and all that. So, I do them every day here, the same exercise so why go up there.

**Wife:**

He went for months and months though didn’t you. He does ebb. I don’t know, he seems to, like I say, 4 o’clock, mind you he gets up early. He’s up at 7; 4 o’clock he seems to have an ebb where he kind of gets a bit tired.

**Interviewer:**

***Yeah. And how do you find doing the exercises every day?***

**Answer:**

Not a problem. No problem at all

**Wife:**

And you have your rubber band don’t you?

**Answer:**

Yeah. And you stretch it and all that.

**Wife:**

He sits here and does it. Religiously does it every day.

**Interviewer:**

***Yeah, okay. And, no, again just thinking about your Parkinson’s. We’ve talked about, you know, your medications and your appointments a little be about exercise, um, are there anything else to look after your health in general, with your Parkinson’s?***

**Answer:**

Fruit.

**Wife:**

Apricots

**Answer:**

I like fruit and things (*diet*) yeah. I don’t want to eat and put on a lot of weight because that wouldn’t be good. I try and keep. That’s why I like walking to keep as active as I can.

**Interviewer:**

***Is that something that you’ve been advised to do or something that you’ve learned yourself?***

**Answer:**

Learned myself. And that’s how I take it.

**Interviewer:**

***Okay. And with all the things that you do for your Parkinson’s, are there aspects that you find difficult or challenging?***

**Answer:**

Not really.

**Wife:**

Yeah, bending. Bend, the only thing I’d have to do, he can’t put his shoes and socks on, but he can’t, he just can’t bend. Um, it’s just awkward, you know, it’s just awkward innit, you know. That’s the only thing I religiously do for him.

**Answer:**

I don’t touch me toes anymore..

**Wife:**

Apart from that he basically. He’s basically, he’s still shaving and things like that.

**Answer:**

I don’t cut the grass anymore.

**Wife:**

No, he can’t do jobs much.

**Answer:**

…..

**Wife:**

Gets a bit frustrated over that. Um, but he tries, don’t you? He does try.

**Answer:**

So, what does health, what do you think a man in a bad state of ….

**Wife:**

Say that again

**Answer;**

Am I in a bad state?

**Wife:**

You’re not in a bad state, don’t be silly. His hands, that hand’s a bit stiff isn’t it, that one?

**Answer:**

Not really

**Wife:**

His hands are stiff, yeah, that hand’s a bit stiff. I notice when he eats, but apart from that he does everything the same; but everything is slow, isn’t it. He tries ever so hard, don’t you, he tries to. You know, every day, each day is a day isn’t it, don’t bother we haven’t got to that yet.

**Interviewer:**

***And how do you manage your prescriptions and getting your prescriptions from your Doctor.***

**Answer:**

We do,

**Wife:**

We take it down

**Answer;**

Take it up; put it into the box and it’s delivered to you.

**Wife:**

They deliver it to the door which, they’ve been doing that for about 10 months now, which, we never asked, which is absolutely delightful.

**Answer:**

And that’s done every time.

**Interviewer:**

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

**Wife:**

In what way?

**Interviewer:**

***Whatever way that you’ve noticed that living with it. Do you monitor your symptoms, or how your medications respond?***

**Answer:**

No

**Interviewer:**

***No, okay. Um***

**Answer:**

The only thing I monitor, try, and keep as active and as fit as I can. And carry on busy as much as I can.

**Wife:**

(giggle) of course, do that anyway.

**Answer:**

So that’s how I try, that may sound stupid. (giggle)

**Interviewer;**

***No, yes it’s a good way. A good approach. (giggle) Um, and what do you do if you have a specific concern, or worry, about your Parkinson’s?***

**Answer:**

Well I don’t do anything cos at the moment I don’t need, haven’t got anything to worry, to do whatever. Just like meet *(PD specialist)* when we’ve spoken she’s been very helpful. Asked me a lot of questions and things like that. I miss her, cos she was very approachfulness.

**Wife:**

Very direct

**Answer:**

I haven’t met the new, I’ve met her, but I haven’t spent any

**Wife:**

The new Doctor

**Answer:**

The new Doctor.

**Interviewer:**

***And do you think the appointments that you have are often enough; not often enough or too often, you know. So, you said the appointments have been helpful, do you think that, you know, what could make it better?***

**Answer:**

Oh yeah, I’d like to meet about every 3 months but that’s not. It was originally, and then it all stretched out (wife: Covid) with this virus coming. So, if I saw her every 3 months, I’d be much happier. *(good*)

**Wife:**

One of the things they did at *(City hospital 1)* that he did do in the beginning, and I think you went twice. There was, we had a letter in to say if he would like to visit the Hospital from 2 o’clock to 3, it was like, um, like a Seminar or I don’t know, a talk, and it was from a Parkinson’s Nurse and she would talk to them. He did go twice; you enjoyed that didn’t you very much?

**Answer:**

That was very good.

**Wife:**

You had to drive there, but that stopped.

**Interviewer:**

***Was that at the beginning of your diagnosis or?***

**Wife:**

Yes, and there were other people.

**Answer:**

….

**Wife:**

I never went. I’d said if you go my son went with him and sat in the car for, you know. But there was another couple and (name) said he took his wife, and I said well I’ll come with you next time. But it kind of stopped, I think because of Covid or what have you. That was quite encouraging cos he was quite good when he came back and said, she said so and so.

**Answer:**

But that was nice time. But that hasn’t been the case now for years.

**Wife:**

But I think that was because of the Covid.

**Interviewer:**

***And what was helpful about, about that day?***

**Answer:**

It was listening to other people with the problem. You were in a group, and everybody had to talk about their path, and it was all being pushed about. And there was enough information to make you think about. It, that was more general discussions. That was it so

**Interviewer:**

***And what sort of things were discussed, those things that were particularly helpful?***

**Answer:**

Well

**Wife:**

Eating wasn’t it. One of the

**Answer:**

Eating, things like that and movement and generally mixing with people. Just general discussions.

**Interviewer:**

**And what was specific about eating.**

**Wife:**

The meat wasn’t it? Do you remember, meat, because the one thing I have noticed in the last 6,10, about a year really, was like I (name) said was the, the meeting brought that up as well, the gentleman was just saying he had to have his meat cut for him. And I think that’s one thing (name) find difficult. He has a lot of fish but, if he has meat, I do tend to cut that, any, you make a joke of it. Cos it’s quite difficult in the beginning, and, but I said, ‘that’s a shame, never mind’, because as I said one of his hands is a bit stiff. And he said this gentleman at this meeting it was the same his wife had brought that up hadn’t she, *(yeah*) and he felt better because he wasn’t alone (giggle).

**Answer:**

Just, you know, things like that

**Wife:**

Just general information. Like you said

**Interviewer:**

***A lot of things people have experienced that helps***

**Wife:**

We’ve never, did we have a booklet. We never, ever received a booklet, or we never had a booklet on Parkinson’s or anything (*no*). We never had any information, only what we’d done ourselves or that our son sent really. And that was, is quite difficult. But, then sometimes you think less information is good because you can keep going over things can’t you, yeah. Um, but you

Answer:

…

**Wife:**

And there are people we know we can phone if we need help, that’s the most, the best thing about it.

**Interviewer:**

**Who would you phone now?**

**Wife:**

If I needed help about the Parkinson’s? Probably *(city hospital 1)* probably, yeah. Yeah, probably the Parkinson’s, cos that’s the only number we’ve got really for Parkinson’s

**Interviewer:**

***Is that the Nurse Specialist?***

**Wife:**

It’s the Nurse, there is a Nurse there, yes, there is a Nurse.

**Answer:**

It’s just carry on and see

**Wife:**

We don’t really have any contact with anyone as such do you?

**Answer:**

No. I try and keep going the best I can.

**Interviewer:**

***Yes, of course. And I suppose what, you talk about all the things that you’ve done with your Parkinson’s and what you’ve learned, what do you think helps you cope with everything that you do with your Parkinson’s?***

**Answer:**

I think the exercising and keeping my mind as clear as I can.

**Wife:**

He reads every day, newspaper. I’ve made a point of going and getting a newspaper every day for him and he sits

**Answer:**

I don’t, I have no interest in computers or anything like that.

**Wife:**

No, he wouldn’t use a computer.

**Answer:**

Because when I was working I had this ….and all that

**Wife:**

Yes, his favourite saying.

**Answer:**

And when I retired, my Doctor down at *(GP surgery)* said, ‘my advice is forget computers’.

**Wife:**

Don’t sit at a computer all day.

**Answer:**

And that’s why I have no interest whatsoever.

**Wife:**

But he loves to read the newspaper from cover to cover.

**Answer:**

And I think that’s more important.

**Interviewer:**

***Yes, of course, yes.***

**Answer:**

So, I might be quite strange to you. (no, no no)

**Wife:**

You’re not strange.

**Interviewer:**

***No reading a newspaper is a luxury, and it’s one we enjoy but we don’t do it as often as we used to. Yes, you’re right I must admit. Um, and I suppose what are your thoughts about how your care is co-ordinated. You know we talked about (City hospital 1) and (local hospital) and times perhaps (City hospital 2), with all your Healthcare Professionals how do you think your care is co-ordinated?***

**Answer:**

I think it’s pretty good, yes overall. Cos all the information that comes from the other Hospitals all goes into system, and if they have any questions they always ring me up. So, I think that type of co-ordination is okay. So

**Interviewer:**

***Yeah, good. And are there, I suppose are there, thinking about the Healthcare System and what you’ve experienced, are there ways you think that it can be improved?***

**Answer:**

I’m happy because *(GP surgery)* are very helpful,.. and I found *(PD specialist)* very helpful. And if I wanted to speak to her she was always willing to talk. So, I’m more than happy, I don’t think I’ve been neglected. That’s how I feel. And hopefully it will carry on.

**Interviewer:**

***Yes Sir, it doesn’t sound like you’ve got anything that you think, hasn’t gone as well as you’d like?***

**Answer:**

No, no I think, I think I’ve always in the past, done things I want. Cos with my job I had an awful lot of travelling to do. I travelled to America; Europe, so I was always away from my children and I felt that time I was covered .. and I don’t see any change.

**Interviewer:**

***That’s good. Um***

**Answer:**

The only thing I would like, if you could do, get rid of Parkinson’s.

**Interviewer:**

***(giggle) Yes. Unfortunately, obviously um,***

**Answer:**

There’s a possibi

**Interviewer:**

***This is the aim. Obviously, do you, (wife) thinks she’s help, but do you think you have help from your family, your friends to help with your Parkinson’s?***

**Answer:**

Oh yeah. I mean (wife)’s very helpful, she’s very good. She’s my number one.. so

**Interviewer:**

***Yeah, good. And do you have***

**Answer:**

The only thing I regret about her, she does need a break. I mean if she wanted to go away on holiday I’d have to get somebody in to look after me. That’s my sadness, but she’s happy to do it.

**Wife:**

I’m not going in anywhere.

**Interviewer:**

***And I suppose are you aware of where to get information (wife – no) if you were to get any help or anything like that.***

**Wife:**

No. Um,

**Interviewer:**

***Is that something you want to know or prefer not to as yet?***

**Wife:**

Um, not yet. I’m not ready yet. Yeah, there are, it’s when you think ‘oh, I’d love a break’, but that’s all because of this, what’s going on anyway. But no, it, it has been difficult and there has been days when you’ve got to go and sit in the corner of the garden on your own for 5 hours. Um, no, not really

**Answer:**

That’s my worry.

**Wife:**

Yeah, he, I do think that sometimes, you know, that we’ve got to be honest and open. I mean not every day’s a happy 100% day. We have days when he disappears and goes for a walk and I don’t know where he is and I think. Sometimes he does things spontaneously, which is not always as far as I’m concerned a good thing, but it’s good for him, but it’s not because I don’t know if he’s sat down in the front room or in the garden or halfway down the road, you know. That, I say to him ‘just make sure you just say’, don’t I *(yes*), things like that. But apart from that, basically no we’re alright we bounce off one another really. And, yeah, there are days when it gets a bit frustrating, it’s not good saying it’s not, and it’s awful to see as well. You know, it’s quite frustrating. Like there are outings we could have, but we don’t because basically we put obstacles in our way ourselves I suppose don’t we? I say no, and he can’t get in my car which is a pain, cos my car’s too low for him and it hurts. He can’t get down to get in and I’m frightened he’s going to knock his head so that’s held us up a little bit. Um

**Answer:**

But that’s alright

**Wife:**

And I don’t drive like his car because its automatic. Um

**Interviewer:**

***But what specific obstacles do you think you put in your way?***

**Wife:**

Like the motorway. Like we have a son the other side of *(city),* and like last weekend we could have gone over. And I said ‘you’re not driving’, and then they say they’ll come and get you and go over, and they’ve got family and you say ‘no, its fine, we’ll give it a miss this time we’ll come in .. a couple of months’. But, you know, that’s the sort of thing you put in the way cos I do think, ‘why drive down the motorway when it’s unnecessary’. We’re quite happy; we’ve got a garden; we can sit in our own garden. That’s the sort of thing you wouldn’t think twice about 3 years ago, you know

**Interviewer:**

***Yeah, of course, and do you think it’s because of the Parkinson’s that (yeah) become an obstacle?***

**Wife:**

For me, yeah, yeah, I think so. Why give him that responsibility when it’s not necessary. But apart from that we don’t, we kind of, do most things. We lead quite a quiet life, yes we lead quite a quiet life really don’t we.

**Answer:**

I don’t drink, I never go to the pubs or anything.

**Wife:**

Since he’s had the Parkinson’s he doesn’t drink any alcohol whatsoever. It was almost like that’s it. Not that he, he doesn’t need it.

**Interviewer:**

***What stopped you?***

**Wife:**

I think he’s afraid of the pills.

**Answer:**

On these pills why mix it with alcohol. I’m taking pills for a purpose, why interfere with that.

**Wife:**

And he religiously hasn’t. He hasn’t had not any.

**Answer:**

It was a decision I made. Nobody asked me to do it.

**Wife:**

No, you did it yourself didn’t you?

**Interviewer:**

***It sounds like obviously that, you know, we’ve given you advice and you’ve the sort of person who sits, listens to what, you know advice and do what is the right thing for you.***

**Answer:**

Yes, I do, definitely, part of my job.

**Interviewer:**

***You think you job, how you’ve worked, influenced what you’re doing now?***

**Answer:**

Absolutely yeah, definitely, I’m sure of that. I don’t know whether (wife) would agree with me>

**Wife;**

Yes, I do, I do agree. It’s just like steps. That’s the trouble we had at the *(city hospital 2),* was it the *(city hospital 2),* or was it *(city hospital 1)*. During Covid anyway we had to visit, and we had terrible trouble. It was a one-way system and if the lift wasn’t working, which this particular time it wasn’t, we had to go down 3 flights of stairs. Now that I found he was very dithery, doddery and that really. he did one set of steps, and I made him turn round and go back up again, and we literally walked a corridor to the next set of lifts, you know. And, which we could have carried on, but it, this, that was I noticed he wasn’t very good with steps; definitely no good with steps wasn’t it? (*yeah*) And it was a struggle; it threw me, it was a struggle.

**Interviewer:**

***I suppose that’s one of the impacts of Covid.***

**Wife:**

Oh yes, it was no other reason, it was just the fact they’d made it into a one-way system and then we had to abide by it. But it was unfortunate that this was the day the lift wasn’t working. Of that something had gone wrong, I don’t know, been taken over I think. And um, he had terrible trouble going up the steps it was awful. Um, and we got, what should have taken us about 10 -15 minutes to come out took us about 45 minutes, (oh dear, oh dear) yeah (giggle) Yes it was just, one of. (*yes, of course*) That’s what made me think about the *(city hospital 2)*, cos the *(city hospital 2) is* on a gradient as well isn’t it so.

**Answer:**

Would you like a drink of water

**Interviewer:**

***No, no I’m okay.***

**Answer:**

You’re sure*. (yes)*

**Wife:**

It’s there if you need it. Apart from that, no he seems, I don’t know what to tell you cos like I said we just accepted it and carried on regardless really.`

**Answer:**

So, what’s my long-term future with Parkinson’s?

**Interviewer;**

***So, with Parkinson’s***

**Answer:**

I want to know, yeah. is it gonna a lot worse I want to know?

**Interviewer:**

**I think, it varies from different people. Um, obviously, it’s difficult for me, here, today, as a**

**Wife:**

Yes, you can’t diagnose

**Interviewer:**

***as a Researcher, um you know I don’t want to be your Parkinson’s Doctor.***

**Answer:**

Yeah, I just wondered if you had any detour from it.

**Wife:**

I personally think we were blessed that he got it so late in life. (yeah) I really do. Um, you know, cos there are people much much younger, and that it must be dreadful really *(of course, yeah*). Fortunately (name) got it very late in life which, you know, is a blessing in disguise really. (*of course)*

**Answer:**

I’m getting on a bit now (giggle).

**Interviewer:**

***Is there anything else you would like to add that, you know, in terms of looking after your Parkinson’s that you think that we haven’t covered so far, um?***

**Answer:**

Don’t think so

**Wife:**

Is there anything that he should, should he be adding to anything. You know, I’m not very good with pills, at all, and I believe in the .. and all the rest of it. Is there anything, an added something, that he should be taking, you know, I often say to him ‘should we be buying some’, you know, I do herbal teas and things, and he quite likes them now. But should he be having an additive of anything, you know.

**Interviewer:**

***Yeah, I mean,***

**Wife:**

Is that just an individual thing again? You feel like

**Interviewer:**

***I wouldn’t want to answer.***

**Wife:**

I know, but you know what I mean, are there, there are things you can add to um, your health plan, um

**Interviewer:**

***And do you think that’s something you feel that you need to do?***

**Answer:**

A difficult one, that. (giggle) My ambition is to get fitter. Be able to do a lot more things, and if there’s anything there that you could help to do that, that’s what I would like. If not, I’ve got to carry on like I am, and carry on and taking everything ..

**Wife:**

And be, eat as healthy as you can. But we don’t, I must admit he doesn’t take any added vitamins or anything, um, which sometimes I feel should we be. But at the end of the day, you know, I think you do get it if you eat properly (husband – yeah) and you have fresh fruit and things like that so.

**Answer:**

Having gone through this, what’s your impression of me?

**Interviewer:**

***Well I think***

**Wife:**

He’s managing it quite well, *(yes, yes, clearly*). Yeah, he is. I’ll answer it for you you he is, to the best of his ability. (yes, yes)

**Answer:**

I want to keep going as much as I can

**Wife:**

You will, you will. If you have a positive attitude you will.

**Answer:**

Okay.

**Wife:**

Won’t you?

**Interviewer:**

***Do you agree with that?***

**Answer:**

Yeah, I think that’s the thing I’ve got to consider. And I’m glad we’re doing this. Cos you gave me the opportunity to talk. It’s a nice thing just to sit down and talk about it (yes) and help. (*absolutely)*

**Wife:**

He doesn’t often get down, do you? He’s not a, he doesn’t often get down do you? (husband – no) He geta a bit frustrating at times don’t you? Um, and he’d like to walk further and things like that. um, he’d love to walk round the Village, but he can’t because a) we have tractors and farms, it’s farmland. B) the pavements are all uneven.

**Interviewer:**

***..I forgot to, with the Walker, how did you decide which walker to buy, that you think was helpful.***

**Wife:**

Went to the disabled shop. And got advice.

**Answer:**

Yeah, we went to the one in *(local area)*

**Wife:**

And tried them all. *(okay)* Because I would, I would say to anyone if they’re buying, if they’re going to get it, make sure that the person that the person that’s putting it in the car goes as well, because it’s not always top of the range.

**Interviewer:**

***So, was it something you felt you need it on your own of did someone tell you, perhaps a Walker, would be safer? What did you think?***

**Answer:**

Somebody told me, and (name) came home with 6 to 8 books.

**Wife:**

He was walking with the stick, and I noticed in the last, probably 6 months, he was starting to do this. No, this, not this. And it was like, I just felt that he was, he needed someone with him all the time. So I suggested that if he got one of those Walkers, with a seat on it, maybe if he was square he would be much safer to go at his own, and then he got nip off down the road and he was independent again. It took 5 or 6 months, well 5 months at least.

**Answer:**

She kept on to me.

**Wife:**

Yeah, I did (husband- and I said). And I said let’s buy one and try one, you know. You’ve got to try these things haven’t you? And there’s no-one around here to try one, so we went to the disabled shop and he loved it.

**Answer:**

It gives you a lot more confidence.

**Wife:**

But it’s not top of the range because top of the range is so heavy, I could not have put it in the car. You’ve got think, you know, it’s as light as a feather; its easy; and he can actually put it away himself around the garage.

**Interviewer:**

***And was there, you know, any Physiotherapist or any help, in the shop?***

**Wife:**

There was the lady in the shop, cos obviously (*in the shop, okay*) it’s a disabled so she’s probably has trained for it. Yeah, and

**Answer:**

And she was telling

**Wife:**

And she was, um, she was good though. She

**Answer;**

Oh, she was very good, she let

**Wife:**

She let you try and she suggested you had this one because it was for going all sorts of roads and going over fields, but I never would have been able to get it in the car, so I said no. so, he,

**Interviewer:**

***So, you got that because you thought, on your own,***

**Wife:**

He chose it himself so it’s like one to

**Answer:**

On my own, and chose what I wanted

**Wife:**

But it’s so light isn’t it?

**Answer:**

Yeah. Because I think it’s important to keep the exercise going and move a as much as I can.

**Wife:**

And since then, he’s been down to the new Estate. There’s a new Estate on our, oh yeah, and the pavements are all pristine obviously, and he walked, well three times the amount than he was here, up, and down the road. Our son took him on the bus though, and it was lovely wasn’t it. He got on; and he walked the furthest he’s ever walked in nearly 3 years.

**Interviewer:**

***And I suppose, in terms of, you know, financial expenses, you know. We have the Healthcare System, but are there other things that you’ve perhaps done for your health that you’ve incurred any financial expenses for that we haven’t thought about?***

**Wife:**

No, not really, we know, but we don’t, no, no. the only other thing that he’s got that helps him, and this was nothing to do with us it was, we’ve only ever had one visit, and it was from a lady when he first was diagnosed and she came here and she said she was the Parkinson’s Representative and she gave us her phone number. Never had any contact with her or spoken to her since, and she said did he need anything and we said, ‘no not really’. And then she said ‘could I make some suggestions’. And one of the things she suggested which, at the time, we thought was not necessary, or he thought was not necessary, which is a godsend. And it was a, err, um, it tucks under the bed and its a bar which A) he holds when he gets undressed; B) he can hold it when he gets out of bed. And its worth a million dollars.

**Answer:**

That is true.

**Wife:**

And that was good. But we didn’t have to pay for it, that came in from wherever, National Health, and it’s brilliant. It really is worth it’s weight in gold because he does use it, *(good*) don’t you?

**Answer:**

Oh yeah.

**Wife:**

And I’ve noticed

**Answer:**

It certainly makes a hell of a difference.

**Wife:**

I pop in and out, you know, while, when he’s getting undressed sometimes or when he’s doing things and he literally does hold it. You can hold it because it’s well secured cos it’s under the mattress it’s safe. And I, he holds it while he’s putting his, you know, and it’s good and you do it when you get dressed don’t you?

**Answer:**

Oh yeah.

**Wife:**

But it’s literally worth a million dollars.

**Answer:**

So that’s the only thing

**Wife:**

And it’s a small piece of apparatus but it’s really good. But that’s all he’s got really. He hasn’t got anything else, got a walking stick.

**Answer:**

That’s right.

**Wife:**

When he left Hospital, after he’d had his, whatever it was he had done, um, he had crutches. You had a bad knee didn’t you at the time as well. You came out with crutches, and they said that he would walk better if he used two crutches. Well he never really got on with them did you? Especially not one on its own, that was when we introduced the walking stick ourselves.

**Interviewer:**

***Who, who recommended the crutches?***

**Answer:**

It was a girl in *(city hospital 1).*

**Wife:**

It was a girl in *(city hospital 1).*

**Interviewer:**

***But after you had the***

**Wife:**

No sorry, it was my fault, it wasn’t his head, his knee. He stood here one day, and I don’t know what happened, but you must have either, he spent a week in Hospital anyway, he couldn’t move from there. I couldn’t get him into the lounge, I had to ring an Ambulance.

**Answer:**

I think the problem was, I was cutting the grass. Came in from cutting the grass

**Wife:**

Pressed on his knee too much.

**Answer:**

And then when I got to the door here I was

**Wife:**

Twisted it didn’t you?. Well he spent a week anyway, and they had to rewalk him, you know, they had to with the Parkinson’s. And I think that was the beginning of the end when it came to the, the garden any way.

**Interviewer:**

***When was that?***

**Wife:**

That would have been 2 years ago now.

**Answer:**

I’d say it was 2 years.

**Wife:**

And he came out on crutches, he didn’t have a walking stick. He could walk alright with the crutches couldn’t you?

**Answer:**

Oh yeah

**Wife:**

And you used to walk with them up and down the road, and then he just got awkward. And he was walking round the house banging everything and it was like, you need a walking stick, so we introduced the walking stick didn’t we? But it’s just things we’ve done ourselves really.

**Interviewer:**

***And how was your experiences in Hospital with your Parkinson’s?***

**Wife:**

First class.

**Answer:**

First class; very good.

**Wife:**

They were excellent, really and truly, we can’t fault. Once you go through the doors, it’s this side of it that’s not so good waiting around and the rest of it, ah, no, you can’t fault it.

**Answer:**

Couldn’t fault it.

**Wife;**

No, you couldn’t.

**Answer;**

Both *(city hospital 1)* and *(city hospital 2).*

**Wife:**

Yeah, he had really, um, and the *(city hospital 2) is* the same. But, um, yeah no we can’t fault, no I can’t fault it. He’s been looked after and when he had his head done, and that was a referral from the Doctor, and that was only last year. Um, he’s been looked after cos he has to go every 6 months now, and we’ve recently been, haven’t we? Couple of months ago. And they test all his bits on him. Have you got any bits, they put a light on you, and he’s been cleared again so he’s fine. For another 6 months. Excellent, can’t, no can’t fault that even with the Covid.

**Interviewer:**

***(giggle) Good. (husband -oh yeah) So from our point of view just to summarise, we talked about some of the things that you do. So, your medications; you having a little notebook to help with your medications. Do you know how many medications you take?***

**Answer:**

Yes, I do.

**Interviewer:**

***How many is that?***

**Answer:**

I have 3.

**Interviewer:**

***Is that just for your Parkinson’s or overall?***

**Answer:**

That’s overall.

**Wife:**

No, 3, three times a day.

**Interviewer:**

***So, 3 different tablets?***

**Wife:**

No, 3 tablets, three times a day; that’s Colcopramine

**Answer:**

Yes, but I also take a Statin once a day. (yep)

**Wife:**

At night

**Answer:**

At night.

**Wife:**

That’s all.

**Answer:**

That’s all

**Interviewer:**

***That’s fine. And so, appointments, and obviously your GP and Hospitals and you talked about having diet and exercise as part of what you do to look after your health and walking around. Is there anything else you think I’ve missed or haven’t covered?***

**Answer:**

Well I run (company), I do all the paperwork.

**Wife:**

He’s still involved in it.

**Answer:**

Still involved.

**Wife:**

And when he sits, he has to sit, literally, you know, I go out cos he needs to concentrate quietly. Don’t use an adding up machine, so he does it all in his head and he, he, you know, he’ll sit for a couple of hours then he’ll have a break and then go to sleep perhaps.

**Interviewer:**

***How do you manage, um, you know, I suppose, what you do on a daily basis like your exercise and your medications with work and after you’ve?***

**Answer:**

I just take each day what I feel like I need to do. I don’t get up in the mornings and I say I’ve got to do this study. I’ll work during the day and when it’s necessary.

**Wife:**

And that changed the day he was diagnosed really.

**Interviewer:**

***Because of Parkinson’s?***

**Answer:**

Yeah

**Wife:**

Yeah, literally.

**Interviewer:**

***Changed how you approach what you do?***

**Answer:**

Yeah:

**Wife:**

Very much so.

**Answer:**

But I mean I’ll think with the business the time’s come when I should pack it in.

**Interviewer:**

***What it is about the Parkinson’s that changed the way you did, was it, I suppose the symptoms or was it the, you know, anything else; the medication; diet. What was it about the Parkinson’s you think that changed the way you did your job? You said it was***

**Answer;**

I don’t think there was anything in the Parkinson’s. I think the time, was my age and the business because I’m coming up, I’ll be 84 soon and I think it’s time to give up work.

**Wife:**

And concentration’s a big thing as well, I think your concentration is another thing. Your concentration span is not as long as it used to be. I notice that with his reading as well. Whereas he’d sit constantly with a newspaper from cover to cover, occasionally now in the week he’ll read three quarters of it and put it down and have a break and go back. Well he used to do that, I think, he can, he could honestly say, it must affect, indirectly, a span. Am I right, I don’t know am I right? Probably.

**Answer:**

Nearly right. (giggle)

**Interviewer.**

***But what about, what do you think?***

**Answer.**

Well I think, workwise, there’s not many people working at my age.

**Wife:**

Oh no we know that.

**Answer:**

And that’s my reason for, the only thing I want to give is get rid of the business. Everything else I want to carry on doing.

**Wife:**

You don’t want any pressure. It’s the pressure

**Answer.**

Not pressure.

**Wife:**

You don’t want to be bothered with it anymore.

**Answer:**

It’s the communication that they’ve not kept up that they should have.

**Wife:**

But that’s todays world though, everybody wants everything yesterday don’t they.

**Answer:**

No, no, because when I set the business up I got all me mates too,

**Wife:**

Yeah, and that’s another thing, can’t do that.

**Answer:**

Three or four …. with the account. We set up everything; I knew exactly what is going on.

**Wife:**

That’s a shame

**Answer:**

That’s all stopped.

**Wife:**

I have to do it in a shoebox now. I have to send it all in a shoebox.

**Answer:**

So that has been a big difference.

**Wife:**

Cos you need contact don’t you?

**Answer;**

He doesn’t communicate to me .. so that is another reason too. And it’s one of those things.

**Wife:**

And it’s the way of the world at the moment. As well. ..

**Interviewer:**

***Thank you very much for talking to me about your Parkinson’s that was very helpful.***

**Answer:**

Appreciate you coming and talking about it.