# Interview P06\_30072021

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| * Diagnosed in 2017 * Only on selegiline for PD * Lives with wife (Caregiver), bereavement of daughter recently * Moved to housing association – near to 2 hospitals and family |

**Interviewer:**

**How long have you been diagnosed with Parkinson’s?**

**Answer:**

Just over 4 years since the diagnosis. Um, although I did think I had it sometime before that. Tremor started before, lost the sense of smell etc so I’ve had it for 7 years before that.

**Interviewer:**

**Several years?**

**Answer:**

Well the recent, just over 4 years since the diagnosis.

**Interviewer:**

**Okay, and how was that diagnosis. Where did you get diagnosed and?**

**Answer:**

I got diagnosed in (town name)

**Wife:**

We paid privately because we couldn’t get to see anybody. There was no available slots at the time.

**Answer:**

Um, and (PD specialist) suggested that I went on Selegeline, medication, which I’ve been on since. Um, I’ve been offered other medication since, which I declined, but I feel the side effects would be worse than the sentence if you like. Although a deterioration has happened probably within the last 6 months, something like that.

**Wife:**

Again, I would say

**Answer:**

It might be getting to the stage where; I might have to have some different medication.

**Wife:**

But do you think though, it might be just our situation. We’ve moved in the last 6 months; we lost our daughter suddenly, and I think all of that together has not helped him.

**Interviewer:**

**Of course, yeah**

**Answer:**

Personally, I think I’ve deteriorated because of Covid. Because I’ve been shielding, and I’ve got Asthma as well. I’ve been shielding for 18 months privately and I got my advice is still much the same; social distance past as ever. So, I think I’ve deteriorated; haven’t got the exercise I used to have; haven’t got the mental stimulation I used to have, cos I haven’t been out much. Um, and I think it has deteriorated more in the last few months.

**Interviewer:**

**Okay, yeah. And just tell me a little bit about, you know, the medications and the decisions and, you know, treatments you’ve had**

**Answer:**

Well, we used to live in (town name) in (city), and at the time, prior to Covid, I was attending, um, an exercise class. It was absolutely brilliant. It was a moveability class; covered everything, which was really good. And I felt really fit and well. Obviously, there was little things like a tremor. Often, since that’s closed down and moving here, I found that my mobility’s got a lot worse, my tremor’s worse, but manageable. Um, mentally, get more anxious; um, I’m not as quick. Mentally and physically, I’ve slowed up considerably. Balance is not very good at all, which was really good before, really good. So, yeah, general deterioration.

**Interviewer:**

**And who arranged that exercise class in (town name)?**

**Answer:**

It was down at the Leisure Centre, um, it’s called Moveability and it was, um, can’t remember exactly who it was, but it was run in conjunction with the Local Authority. Linked up with the NHS.

**Wife:**

It was a Parkinson’s one wasn’t it?

**Answer:**

We had a Parkinson’s course, 12-week course at the local Hospital, which was an hour of exercise, an hour of talks by professionals, various things which then led onto the exercise class. But apparently, I’ve been, I’ve been chatting to the OT here, but obviously because of Covid they’ve closed them all down, but I think they’re starting to start them up here again. So, should be in touch so hopefully I will get some exercise, physio exercise, cos I feel. If your body’s healthy and fit, your mind has got a better chance to be active. But, I mean, another thing is fatigue, tremendous fatigue and it comes in a wave. Mornings I’m good; this time, round about this time of day I start to hit a wall. Um, not sure medication can cure anything in that respect.

**Interviewer:**

**So, you think exercise is an important part of looking after your Parkinson’s?**

**Answer:**

Oh, very much, very much. For me personally. Um, because I’m capable of it. I mean a lot of people that have really quite disability with Parkinson’s. Um, apart from the fatigue I think I’m quite capable of doing a good exercise class.

**Interviewer:**

**Covid obviously has had an impact on you?**

**Answer:**

Oh, terrible impact. But I think it’s impacted a lot of people in various ways.

**Wife:**

Mentally as well, I think, not just

**Answer:**

Yes. I’ve very slow now, I can’t, I can’t cope with too much happening at once. Where I was able once, to be able to think about different things at the same time, now I can more or less concentrate on one thing at a time. If things start to get too much, I start to get anxious; probably angry. Um,

**Answer:**

Also, my dexterity’s gone. Um, which again, causes a great deal of anxiety and anger cos you can’t do things. There’s a lot of, sometimes involuntary movement, but I can’t write very well. Um, sometimes on the keyboard quickly press the wrong button without wanting to, which has happened. So, it’s just generally things like that, um; I do stumble, trip, generally my right side is it. It’s my right side that’s got the stiffness in it. Things like shaving is becoming difficult. I use an electric razor, and you’re supposed to run it in circles, so I’ve never been able to do this because I get so far, just goes out of me hand. Um, writing, it’s terrible now, can never write. Start off thinking you can do it well, but it dribbles off.

**Interviewer:**

**So, thinking back, about, when you first heard you had Parkinson’s disease, did you get much information about, the condition?**

**Answer:**

I’ve had lots and lots of information about various things. Some which apply to me, some which didn’t. Um, there’s a lot on, it’s very difficult to get on the system at the beginning. Um, but once you’re into the system, there’s so many avenues that open up.

**Interviewer:**

**What do you mean when you say system?**

**Answer:**

Well first of all you’ve got to have some support, work out, whether your Nurse Practitioner or um, Consultant or whatever. But there’s, also I’m a member of the Parkinson’s UK and there’s Parkinson’s Leisure Groups, which obviously aren’t happening at the minute, not for a while I should think. And it’s just getting to know where to get this information, cos there’s a lot out there. Um, we’ve had all sort of talks on aids; ability aids such like.

**Wife:**

Would you say that Hospital, the 12-week Hospital thing, I thought was amazing? It opened up so much for him.

**Answer:**

No, it wasn’t just for me, it was Carers as well.

**Interviewer:**

**That was in (town name) was it?**

**Wife:**

That was amazing again, cos you had all these different people. Some people we just taking their medicines wrong, you know. Some people would get this freezing thing, and you watched. And I kept in touch, so I see how they’ve changed. (husband) has been very lucky in some ways, um, he hasn’t changed as much as others.

**Answer:**

I mean when I went to (town name) I couldn’t find. I went to the GP and was referred to a Consultant, but the waiting list was so long, and I thought I’m not going to see anyone. I was involved with a Research, I think it was London University on, um, to see with eyesight and cognition of the eyesight which I’d started before we moved to (town name). I was contacted and they said this same thing in (town name). So, I went along as I did yearly, and I went along to the second one and it was the lady I talked to in there, and talked in there that then put me in touch with the Nurse Practitioner and then from there it sort of got.

**Wife:**

It was wonderful.

**Interviewer:**

**Was that before you were diagnosed, or just after**

**Answer:**

I was, after I was diagnosed, cos we moved away. Moved from (city name) to (city name), then back again

**Interviewer:**

**So initially your GP referred you, but you said the waiting list was very long, so just before the diagnosis itself?**

**Answer:**

No, it was after the diagnosis.

**Wife:**

There wasn’t a lot of help from the GP to be honest.

**Answer:**

No, when I first went to the GP in (city name), she referred me. Again, I couldn’t get to see the Consultant, so we went private. I saw the same Consultant, and once I’d seen him privately and been diagnosed, I then went on his NHS list. Which then gave me the Nurse Practitioner and all the rest. And then we moved to (city name), again it was just trying to get into the system.

**Wife:**

I think we knew before he actually was diagnosed.

**Answer:**

Oh, I knew.

**Wife:**

Cos we was on holiday, and you were sitting doing this, and I kept looking at him and I was thinking ‘shall I mention that or not’. And then you said, didn’t you?

**Answer:**

I think it was about, could have been 6 or 7 years prior to diagnosis, I lost my sense of smell. I was having a lot of operations on my hair, and I put it down to the medication. But no one ever discussed it with Parkinson’s really, but apparently it is one of the pre-cursors of Parkinson’s. So, I probably could have had treatment long before.

**Interviewer:**

**Yeah. And in terms of the information, you know, once you said you’ve had access to it, do you think it’s been easy or difficult to understand, from your point of view?**

**Answer:**

It’s easy. What you got to figure out is how the symptoms affect you personally, because there are so many different symptoms. So many people are different, really different. Then you’ve got to try and work out what symptoms is Parkinson’s, what symptoms is age or your personal physique.

**Wife:**

That’s a big thing to do, try and work out. Because he’s older, you know, or whether it’s the Parkinson’s, that is difficult.

**Answer:**

Um, take eyesight for example deteriorates up to a certain point.

**Wife:**

That is difficult.

**Answer:**

It deteriorates, does it have anything to do with Parkinson’s, because getting the physical part of your body and the mental part joined, so the message comes straight through is much slower to react, so you tend to have to concentrate. Like driving for example. Once upon a time I could drive along; I could look out the window and see other things, I can’t now. Is that age or Parkinson’s?

**Wife:**

Yeah, and I try not to talk now about things, as you do. Chatting away. I tend not to do that now, cos I know he’s saying he’s got to really concentrate, um.

**Answer:**

I can’t drive and reason at the same time. I have to focus on driving

**Wife:**

You’re very good still.

**Interviewer:**

**In terms of, you know, we talked about what is part ageing, do you have any other medical conditions other than Parkinson’s?**

**Answer:**

I’ve got industrial asthma. Um high blood pressure which is normal for this age. Um, enlarged Prostate, which is nothing to do with anything really. Um, that’s it really.

**Interviewer:**

**So, what medications do you take?**

**Answer:**

I’m on Finasteride for the Prostate; Losartan for the high blood pressure and I’m on inhalers for the asthma.

**Interviewer:**

**And your Parkinson’s you take**

**Answer:**

Selegeline.

**Interviewer:**

**How many times a day are taking your medication?**

**Answer:**

Just the once. I think it’s 10mg isn’t it? Once a day.

**Interviewer:**

**And what about the rest of your medications. How many times a day**

**Answer:**

Um, Finasteride is once a day; Losartan’s once a day; inhalers two puffs once a day. Or the Ventolin I would take if I needed it, which principally I haven’t used much because hasn’t done anything.

**Interviewer:**

**And how do you manage your, how do you find managing your medications and prescription and?**

**Answer:**

Again, I can sometimes get out of sequence of things. So, I get halfway through. For example, in the morning when I’m in the bathroom I would shave; wash; hair; teeth; medication. Sometimes I get halfway through and I forget which ones next and what I’ve done. I think whether the mind wonders or whether I just lose that concentration, I don’t know. Tablets are pretty good as I’ve only got the 3 tablets, so, I mean, (wife) normally puts them out. So, I take them quite easily.

**Wife:**

He often forgets to put his towel back. Just little things but what I have noticed recently, he goes to a drawer and he opens it and gets what he wants, and he walks off. He’ll open a packet of something, and he leaves it all on the side and walks off. Now, he would never have done that years ago, but it’s everywhere now. I’m going shut this drawer; shut that drawer.

**Answer:**

I did really sort of associate that with the age, but since chatting to someone else we know that’s got Parkinson’s…

**Wife:**

Her husband does it as well.

**Interviewer:**

**Answer:**

Does the same. So that might be part of it, don’t know.

**Wife:**

It’s just one of those things.

**Interviewer:**

**Do you find talking to people who’ve had Parkinson’s, you know, you’ve said the Groups and.?**

**Wife:**

They’re wonderful

**Answer:**

They’re tremendously beneficial.

**Wife:**

Wonderful.

**Answer;**

Cos you can associate your symptoms with their symptoms, whether they’re the same or different; how they cope; what they do. Yeah,

**Wife:**

It’s amazing isn’t it, yeah

**Answer:**

Really, really good.

**Interviewer:**

**And how’s that, you’ve moved quite a lot and how has that been when moving places.**

**Wife:**

It stopped here. Once we got here didn’t it?

**Answer:**

Its once you get into the system, things open up to you. Um, but again I think the Parkinson’s Group, here, hasn’t met since Covid.

**Interviewer:**

**Yes, of course.**

**Answer:**

So, I’m hoping that will start up again.

**Interviewer:**

**Since moving here it’s been an odd experience for you I suppose.**

**Answer:**

Yeah

**Wife:**

Life’s been difficult because we’ve been trying to decorate. Lots of problems and things. We just want to get it finished, you know, so we can say, ‘right, we can now go out and do bits and’. He’s too tired at the end of the day to go for a small walk, which is wrong really but, we do have to get it to a level, you know, we’re okay with it. And that’s a bit difficult isn’t it?

**Answer:**

Where once upon a time I could decorate a room probably in about 2 weeks, now it could take a month. Cos I do a bit and sit down a bit; do a little bit more, sit down a bit. Now I’ve got to the point where I leave it.

**Wife:**

I do think that’s the Covid, cos I’m sort of very similar. I think other people are finding that (absolutely, yes) tiring.

**Interviewer:**

**Yes, it’s the change**

**Wife:**

Yes, it’s a big change

**Interviewer:**

**And just thinking about, all the other things that you do for your Parkinson’s. What aspects do you find most difficult or challenging? Or are there aspects that you do find**

**Answer:**

Um, movement and balance. Um, I sometimes wander around, stumble a lot. I think, again, that would improve with exercise, which is the balance. Um, mentally slowed up. Um, I try and do a lot of crosswords and puzzles, I’ve got loads there, just to keep your mind active. I’ve noticed a deterioration in my ability in that sort of thing. Cos I used to be very good at puzzles, crosswords, and all that. I find it very difficult to

**Wife:**

You’re not reading are you very much?

**Answer:**

No, I used to read quite a lot, but can’t seem to get into reading anymore; can’t seem to read, um. If I’m reading a news item for example, which goes on and on and on in the newspaper, I get into the first couple of paragraphs, I lose interest. I just read headlines, now whether that’s

**Wife:**

You’ve said that to me

**Answer:**

I’m not sure whether that’s just age or Parkinson’s, it’s difficult to say. Um, not really chatted to anyone else about that, so I wouldn’t know what their experiences are.

**Wife:**

No, we haven’t have we. About that, no.

**Interviewer:**

**I suppose, you know, if you do have a question or concern about your Parkinson’s, who would you, who would you go to for an answer:**

**Answer:**

Um, I couldn’t actually say the GP, but I think, um, probably the Consultant but I’m not due to see him for another 5 months. Um, unless, things deteriorate rapidly then I’ve gone to the GP. He’s written to the GP with the, um, possibility I might need to go on some other medication. He’s already drawn up that prescription. So, if I needed that I could go to the GP and get that prescribed.

**Wife:**

That was good wasn’t it.

**Answer:**

Yeah, I’m just concerned, where I say I’m quite happy just prodding along until the next time I actually have a face-to-face, cos this was a telephone appointment and I’d like to see him face-to-face. Cos I think he needs to see how I’m moving about.

**Interviewer:**

**And have your appointments changed with Covid. Obviously, we talked about the telephone**

**Answer:**

Well yeah, sometimes it’s all you get. A letter to say you’ve got and appointment; then you get another one to cancel and make another one.

**Wife:**

But that was our choice, to be honest, I didn’t want (husband) going to the hospital. I thought it was too much of a risk. Um, quite frankly just to have a conversation. If I thought he needed medication or something completely different, I think that would have been a different thing. But both of us felt safer not, so we went for the phone call.

**Answer:**

I have quite a lot of trouble with my throat. Um, talked to the Nurse Practitioner in the GP Surgery. She wanted to send me for a throat scan, which I declined cos I didn’t want to go in the Hospital. Because we, she wasn’t sure if she had ….out, but I think it’s Parkinson’s, cos eating is getting a little bit. What do you think, is it dexterity? It’s not swallowing so much, its more not being able to, I don’t know, it’s odd.

**Wife:**

Well I think it’s two things. One you can’t smell and one you can’t taste. Well that to me must be very difficult to live with. I’m surprised you eat the varied things you eat.

**Answer:**

Well I tend to drop things, and the dexterity has gone.

**Wife:**

Um, oh well, that might be something

**Interviewer:**

**Well how do you manage that, how to you try and manage it**

**Answer:**

Um, just perseverance. Basically when you drop something, just carry on. I don’t salivate a lot, well I salivate a lot, but I never dribble, which is an obvious sign. Um, the throat thing, I think, personally, I think it’s the inhalers I have been taking them for years. I just think it irritates the throat, and just sometimes food or drink can catch my throat.

**Wife:**

Chocolate’s one isn’t it:

**Answer:**

Chocolate and ice cream for me and all. Funny enough, the only thing I can taste is sweets.

**Wife:**

Raspberries you love, don’t you, cos you can taste them.

**Interviewer:**

**Have you changed your diet? because of it**

**Answer:**

No, no. I started; I eat well. Hasn’t affected my appetite. Um, or my digestion system’s fine. I mean that all works fine, so, I just, eat.

**Interviewer:**

**And um, tell me about your experiences with, your GP or, how’s that been?**

**Answer:**

Yeah, um, Parkinson’s is not really been explained too much by GPs. Um, all other aspects of my health, I’ve had some really good GPs. I can’t complain. I’ve had 7 over the last few years; every one of them’s been really good so I can’t complain. Um, this Surgery we’re at now, pretty thorough, you know, I’ve had a lot of conversations on the telephone about the Asthma, like blood pressure.

**Wife:**

Things we never thought they would actually bother to, you know, go forward with but they were straight on the phone. I mean everything was amazing.

**Answer:**

But, um, as far as, I think, Parkinson’s is concerned probably because it’s a complex subject, and you really need to see a specialist.

**Interviewer:**

**So, the GP looks after your blood pressure and your asthma and your Parkinson’s is mainly looked after by your PD Specialist (yeah). And um, you talked about, you know, they call you. How have you found the telephone appointments with your GP?**

**Answer:**

Ah, you know, I guess they’re quite thorough. I still think I’d prefer face-to-face, cos I think body language is a big sign about things. And you can get a better rapport with somebody you’re sitting with, rather than this digital

**Wife:**

You don’t like the telephone though do you?

**Answer:**

Nah.

**Wife:**

He’s not a telephone person. Um, at all

**Answer:**

Actually, not a very good conversation side, believe it or not. Um, so I find it difficult, quite difficult on the telephone, from my point of view. And I’d rather face-to-face, but as it happens we’re just getting back to that hopefully, hopefully.

**Interviewer:**

**And, um, you know, and your moves, how have you found your care’s been co-ordinated, you know, moving from one GP to another and moving areas. How has that been from your point of view?**

**Answer:**

Not very well. Nah, it’s been a problem because when I first went to (city name). I mean obviously I was referred to the Practice Nurse to see this Geriatric Consultant. He didn’t have any information on me whatsoever, and I thought that’s rather odd cos in this day and age you think you’d be able to transfer records very quickly. But what I actually had to do was I actually had to get in touch with (city name), for them to send the information to (city name), um, which they eventually got. And since I’ve come back here, I think, I don’t think anything‘s been forwarded cos, when I’ve talked to the Consultant he was basically, he really didn’t know my situation.

**Interviewer:**

**You said the Parkinson’s Consultant? (yeah) okay.**

**Answer:**

I think the records are not really been transferred quick enough. Because they speak to you they should really have a good idea of your ailment

**Wife:**

History, shouldn’t they

**Answer:**

Yeah, I mean it’s important that they know what’s going on. But, um, I suppose it’s a long process. In this day and age everything seems to, it’s supposed to be easier and quicker, but it’s getting harder and slower

**Wife:**

It’s harder

**Answer:**

You know, paperwork used to be posted a letter, and it got there within the next day or so. Now with digital never gets there for months.

**Wife:**

We found this when we moved. We did everything they told us to do; every different department and we sent it and they still had no idea; they didn’t have the letters; they didn’t, it was just horrendous. It was the worst move, that way, that we’ve ever had.

**Interviewer:**

**Moving here?**

**Wife:**

Yeah, yeah, because people just weren’t connecting with you. You’d phone them or you’d write, you’d do whatever and they’d say, ‘oh, we never received that’. And you’re like, agh,

**Answer:**

But there is a lot going on.

**Wife:**

There is, and Covid been

**Answer:**

With the National Health Service, there’s a lot going on.

**Interviewer:**

**So, you moved in the middle of**

**Wife:**

December

**Interviewer:**

**Oh right. Right in the peak of Covid.**

**Answer:**

Fortunately, that was between two lockdowns. There was the November one and there was one after Christmas. Otherwise, we would not have been able to have moved. We’d have still been sat there.

**Wife:**

I still don’t know if, I still don’t know. If we hadn’t have lost (daughter) the way we did, I think (husband’s) Parkinson’s may not have been quite so bad. I think it had such an effect on us, as people, and then lockdown

**Answer:**

Absolutely

**Wife:**

And then lockdown and all the other awful things that happened, you just sort of got. We came back to be near our family because

**Answer:**

It was difficult because she didn’t live here, she lived in (city name). There was a lot of dealing, tragic death shall we say, unexplained. I had a lot of chats with the Coroner; with the Police; and different things. And I had to deal with all her business details and that, and I coped really well with that.

**Wife:**

You did, amazing

**Answer:**

I couldn’t do it now. I’d be confused and ..

**Wife:**

I was on the floor, and he did all that and, I mean, I

**Answer:**

Funeral Directors and everything.

**Wife:**

Everything, it was just,

**Answer:**

I did the whole lot.

**Wife:**

He, and you did cope with it well but, I just think. A big percentage of his Parkinson’s has been the effect of that and also here as well, you know. We had a leak; and we had this and something else, you know, it’s just all added on top every day. As soon as you get three things done, two more appear. And I think for him, now, my idea is to give him as much release as I can. Try to take things away that stress him, cos I

**Answer:**

I had an appointment in (town name), Mental Health Clinic, or something

**Wife:**

Yes, Mental Health Team

**Answer:**

Which I was interviewed by the Psychiatrist. And I did certain tests, and the upshot of it was, I didn’t have Alzheimer’s or Dementia. My problem was stress.

**Wife:**

What they said was, um, I’m trying to think what they said. You were having, what did you call it,

**Answer:**

Fogging

**Wife:**

Fogging. He was having fogging moments, and we couldn’t understand why, and this is what she came back with. Once we’d told her everything. We had a son that had problems and it was quite severe, and then of course we lost (daughter). And she just thinks it was a complete overload, you know, for him. Um, and that’s what she came up with. I mean 99% your test were right; you were doing everything so

**Answer:**

Oh yeah, the memory test was good, but I still get, what was it, it’s like a light-headedness, like, I call it fogging. The brain just sort of, you’re in your own little world for a while, you realise its

**Wife:**

About 8 or 10 years ago, we were out, I was working at the time. And, I was in a shop and (husband) said, ‘you’d better hurry up and get back’. So, I started marching long a bit quicker, and I turned round, and he was in the middle of the aisle and he was just. And I remember thinking, ‘how bizarre is that’. it was like he was in his own little world; walking down this thing; and he made a joke and said it was cos he was bored in the shops. But in actual fact, I truly believe that could have been Parkinson’s then, because I see it in him now.

**Answer:**

It’s like wearing a diver’s helmet. You can see, but you can’t really, you’re not really hearing or touching or its

**Wife:**

And I recognise that, don’t we, now, yes, interesting

**Interviewer:**

**And, um, how have you found your appointments with your PD Specialist, how’s that been?**

**Answer:**

I suppose they must have a lot of work to do. I think probably, instead of seeing a Consultant once every six months I think, perhaps three would be better. Um, the actual inter, the appointments that I’ve been to, yeah was okay. I mean, asked me questions; did some tests

**Wife:**

Lots of changing of dates. Lots of times. (yeah) You know, cancelled the appointments; remake it another time; cancel it again. I think we had 3 with the phone call one, yeah. I think, yeah. So that can be, a bit annoying.

**Answer:**

Mostly you’re given, um, a Geriatric Consultant, and not an actual Neurologist. Um,

**Wife:**

Like a shortness of Neurologists isn’t there

**Answer:**

Well, this is the problem (city name) only had one to cover the whole of (region name). I think they’ve employed another one since but, getting to see them’s impossible. Um, so that’s a difficulty.

**Interviewer:**

**Have you seen both Neurologist and Geriatrician with a PD Specialist or?**

**Answer:**

No, I’ve just seen, um, one specialist; one Neurologist and the others have been Geriatric Consultants.

**Interviewer:**

**Did you notice any difference in your experiences?**

**Answer:**

Um, well obviously how I think, my mind anyway, could be the Consultant is much more specialised, knowledgeable than the Geriatric Consultant. Although they did know all about the symptoms etc, but I’m not so sure they’re sort of on top of it if you like. Um,

**Wife:**

Do you remember the Parkinson’s Nurse saying, ‘although she agreed with the Consultant over most things, even the Consultant didn’t always recognise some of the things’ this is what the Nurse said to us once (giggle), and I thought wow.

**Answer:**

The Nurse Practitioners are very good. I mean, basically, once you’ve seen the Consultant you don’t see them again. Cos they’ve done their job; they’ve diagnosed.

**Interviewer:**

**Is that the Neurologist?**

**Answer:**

Yes, Neurologist, sorry. Yeah they’ve done their job; they’ve diagnosed it, next is the treatment, and the treatment is left up to the Specialist Nurses.

**Interviewer:**

**So, you said, ‘left up to the Specialist Nurses’?**

**Answer:**

Yes

**Wife**

From our experiences

**Interviewer:**

**Tell me a bit about that when you’re?**

**Answer:**

I mean the one is (town name) was very, very good.

**Wife:**

Um, she was.

**Answer:**

And she was very thorough and made some good reports. Um, the one in (city name), probably wasn’t as hand on shall we say. She was approachable, um, if you needed anything she could point you in the right direction, but she didn’t really delve deeply into each individual did she when you went to see her. Um, but they do point you in certain directions, um, obviously since I came back here I haven’t seen one (of course), so I’m waiting.

**Interviewer:**

**I know you mentioned slightly that the last consultation they recommended some medications that you could take if you felt you needed**

**Answer:**

I think it was Levodopa.

**Interviewer:**

**Yes, so just tell me about, you know, your decisions. I know you said you want to try and hold off medications as much as possible. Tell me, from your point of view?**

**Answer:**

My personal point of view is, I think a lot of my problem I need to be fit. And I think a lot of my symptoms will alleviate by being fit. And I’ve always thought that. cos a lot of it is movement, balance, posture and I think with that comes a sharper mind. Um, other than that, I’m not sure cos of the side effects of some of these medications are quite severe. And I’ve seen, obviously we’ve met a lot of people taking Levodopa etc.

**Wife:**

Hasn’t been great has it.

**Answer:**

No, um

**Interviewer:**

**Your experience of seeing other people with the side effects (yeah).**

**Wife:**

We spoke to their partners, you know, saying how since (name’s) been taking so and so, you know, he’s really deteriorating, and you think, ‘oh god’, you know. But that might not be anything to do with it, it might be just their perception of it you don’t know.

**Answer:**

I got high blood pressure, but that’s stabilised. That’s not affected; bowel movement etc. is absolutely normal so I got no problem with that. now these things can be affected. Appetite’s fine; I get a little bit of fatigue, but I’ve seen people that actually fall asleep doing things when they’re on these medications.

**Wife:**

Yeah, that is something that the people,, partners have said to me.

**Answer:**

Until the symptoms get really severe, then I prefer not to, um,

**Interviewer:**

**And do you monitor your health?**

**Answer:**

Ah, yes. Take my blood pressure every Monday. Err, temperature; weigh myself every week, so keep a nice stable.

**Interviewer:**

**And how do you find doing that?**

**Answer:**

Ah

**Wife:**

Well we do it together don’t we

**Answer:**

Yeah. We have a little routine (giggle)

**Wife:**

Yeah, all these little routines (giggle)

**Answer:**

It’s been fine.

**Interviewer:**

**You don’t find that difficult or challenging?**

**Answer:**

No.

**Interviewer:**

**And, um, have you had contact or access to other Healthcare services, so physio, Occupational Therapists, Speech Therapists?**

**Answer:**

Yeah, I’ve had the Occupational Therapist here, yeah. Um, I did see a Speech Therapist in (city name). She was quite happy at the time, that I was okay, but she did say that in a few months if I went back I could have courses on um, telephone conversations and then you’ve got to start singing them. I never went back for them.

**Wife:**

There was one thing we noticed, didn’t we, when that was offered to you, somebody else had had it. Her husband had had it, and at the time of doing it, it was brilliant. But she said as soon as he stopped, it just all went back to. So, it was great at the time but not, so we sort of thought, um,

**Answer:**

Yeah, I’ve seen one or two people. What as the other one? Who was the other guy I saw?

**Wife:**

I don’t know

**Answer;**

Was that for speech, or something else.

**Wife:**

I can’t remember that one.

**Answer:**

I can’t either. Um, I did, cos I did attend (city name) cos I lost my finger. I’ve got phantom pain in this finger.

**Interviewer:**

**You’ve got, oh right**

**Answer:**

In this finger that’s missing. Um, I have a lot of pain and it was suggested Deep Brain Stimulation, yeah. So, I went up to (city name), saw the Consultant I had (surgeon name).

**Wife:**

He was absolutely off the wall (giggle) He was sitting in the reception area with another Professor, and he was, well it was unbelievable. And you’re thinking, he was ever so intelligent, and I was think

**Answer:**

And he suggested it could well offer me a place, but apparently the Local Health Authority wouldn’t fund it. And it wasn’t for Parkinson’s, but I believe he did it for Parkinson’s.

**Interviewer:**

**They do, yeah.**

**Answer:**

But in my case I don’t think my symptoms would be anywhere severe enough.

**Interviewer:**

It’s interesting the phantom pain, that’s an interesting

**Wife:**

Oh, it’s horrible. Every day he’s like this.

**Answer:**

I’ve had every treatment known to man and it just doesn’t. I mean I had one of the Head Specialists (at city name) that was, um

**Wife:**

He dealt with trauma from the War, you know.

**Answer:**

Afghanistan, the army.

**Wife:**

Troops, and .. all of them.

**Answer:**

He’s at (hospital name). And he worked there. And he’s done several operations and just moved the nerves around and all sorts. But it’s never been approved, just live with it. And I did take a lot of medication at the beginning, but it sent me completely off the wall. So, I said, it’s now worth it, I’ve got to put up with it and have some quality or just sit like, and not have pain but just not being able to, have a

**Interviewer:**

**And have you ever needed to get help at the week-ends or, you know, overnight for your Parkinson’s or things?**

**Answer:**

No, I think (wife) always watches me, because I do head out to the toilet sometimes once, sometimes twice, and she watches me cos she’s a light sleeper anyway. Cos when I first get out of bed, I’m tight; the legs are tight, and you’ve got to sort of stand and stretch and can stumble around. We have a night light, cos I’m going to the toilet during the night.

**Wife:**

Again, you know, that’s another thing, seeing somebody else that does the freezing. So, I’m sort of aware what they’ve told me to sort of watch. It’s very helpful when you do speak to people.

**Answer:**

And I’ve been getting a lot of cramps

**Wife:**

Yeah, a lot, don’t you?

**Answer:**

My feet and my legs. Whether that’s Parkinson’s, inactivity, circulation or what, I don’t know. I’ve never been to the Doctor with it. I didn’t want to bother him with anything else.

**Interviewer:**

**There’s a few things you said that you haven’t been to the Doctor about, is that, I suppose is that by choice, is that**

**Answer:**

Well I sort of decided myself whether I think I should or shouldn’t. Whether it’s a Parkinson’s symptom or not, um, otherwise I’d probably have gone through a lot of tests. But again, because of Covid, very reluctant to go to the Doctors. We’ve been for our Flu Vaccines and stuff like that, but other than that we haven’t really been to the Doctors for a very long time.

**Wife:**

I had to go

**Interviewer:**

**Do you think you would have, if Covid?**

**Answer:**

Quite possibly, yes. Cos as I say I prefer a face-to-face. Um,

**Interviewer:**

**And I suppose, what do you, you know, what, how do you work out whether it’s your Parkinson’s, or as you said, other things or age. What have you used to find that information?**

**Answer:**

Um, well, yeah. You can look at the internet, but it’ll tell you all sorts of things on the internet. Um, just personal judgement. If I can live with it, I don’t worry about it; I get on with it. Um, obviously if it really affects me, I would obviously seek help but it would have to be quite serious for me to do that.

**Interviewer:**

**And how’s looking on the internet for how has that experience been**

**Answer:**

For some things it, I mean you can get a lot of information, but you can get a lot of false information.

**Wife:**

You have to wheedle it through don’t you.

**Answer:**

You know I’ve been told, oh kind of CBD Oil, all this sort of thing. And I have looked at it, but there isn’t any clinical trial that’s really come up with anything positive in that respect. There’s lots of different things like that, but it’s more hearsay. Um, now people say Acupuncture for certain things; and people say medication whatever. And there’s lots of different therapies sort of thing, alternative therapy. Some people say they’re good; some people say they’re not but, personally, as long as I can get on with my life, I’m not gonna

**Wife:**

No, I think the hospital….

**Answer:**

I don’t what to try things I’m not happy with

**Interviewer:**

**And, you know, what are your thoughts about how your care has been co-ordinated between, you know, the different health professionals that you’ve seen – the GP, the Specialist**

**Answer:**

I think the communication between different places is not great. Once, like I say, you get into the system it’s fine. Covid had a massive, can’t say it, effect on, on my ability to see them or them to see me, and I think they’ve got a lot, also the NHS, probably needs more people, more specialised people. Cos they’ve got so much to deal with, and I think, like a lot of people will say, that our treatments have been pushed to the side because of Covid. So, it’s a particular time in life, in most people’s lives, they’ve never had anything like this before. And I would say prior to that, yeah you could somebody pretty quickly couldn’t you, or not a problem with it.

**Wife:**

I thought it was outrageous that you couldn’t see a Specialist, and there was no open appointments. And then I said to (husband) we’re going to have to pay, so we paid, and then the Consultant sat there and said, ‘oh, you should have phoned me up and I could have got you in’.

**Answer:**

Apparently the system in this part of the world is you have to go out to the Appointments Team. And they have a list of so many people, they release so many appointments a month, and you’ve got to keep ringing and ringing and ringing, because the volume of people, it could take years.

**Wife:**

That’s quite distressing for somebody.

**Answer:**

But if the GP had written to him personally, he could have seen me. Cos he said, I’ve got vacancies.

**Wife:**

We had to pay £500 as well, that’s a lot of money.

**Answer:**

He had vacancies, but the appointments people didn’t.

**Wife:**

For one chat

**Answer:**

Cos they’re only allowed so many slots in a certain length of time

**Wife:**

I thought that was terrible actually. Um, and our family as well, made comments about, um, how unbelievable that is in this day and age that we didn’t have, at least an opportunity to see somebody at some point. You don’t expect it right away but,

**Answer:**

I know they’re short of staff and all that.

**Wife:**

They are, terribly.

**Interviewer:**

**And have you had any financial expenses because of your Parkinson’s?**

**Answer:**

Well I mean, for all the exercise classes, we had to pay something each week to attend because it was a private Leisure Centre. Um, apart from that, we haven’t really bought anything, I

**Wife:**

No. you had a couple of odd pens to help you, but not really.

**Answer:**

Yeah, things like that … purchase. But, err, other than that

**Wife;**

But you just find other ways of doing things. Like, if you can’t do something, he’ll sit down and do it; like shoes, he has trouble with his shoes. Quite often he’ll go to put the back of his shoe on, and he’s almost falling out the door, you know. And that’s something I’m thinking about getting him a stool for him to. We’ll quite good at working round things, I think we’re probably too good actually. (giggle) That’s the truth of it.

**Interviewer:**

**And I suppose you feel overstretched with what you have to do to manage your Parkinson’s?**

**Answer:**

It might be fatigue, but yes. Um, it’s a new way of living shall we say. You’ve gotta sort of work slower, much much slower, but I get there but it takes a long time.

**Interviewer:**

**I mean what has the impact been on your life and your Social Networks?**

**Answer:**

Social Networks nil. I meant being as I’m like this you do get quite a community. I know we haven’t been here long, there’s always someone to talk to if you want to talk to them. You know, people passing all the time.

**Wife:**

We do tend to keep out of it cos it can get a little bit, you know

**Interviewer:**

**Is this a**

**Wife:**

Development, Housing Association. So, its

**Answer:**

Yeah, yeah. its over 55s.

**Wife:**

It’s a very safe environment isn’t it.

**Answer:**

Yeah, its quite a friendly kind of environment, but obviously again, it’s Covid so couldn’t re-open, couldn’t do this, couldn’t do that.

**Interviewer:**

**Was that a decision to move into a Housing Association?**

**Wife:**

Yes, because we’d lived in one before and we thought it would be the best thing for us.

**Answer:**

Previously we rented private, but, its not secure. You get to an age when you want Security of Tenure. And your one way of doing it is, Housing Association. And Local Authority’s very difficult, but they don’t help very much do they.

**Wife:**

No. We were actually very lucky that the couple that lived in here before put a new kitchen in; done lots of things so we’re just finishing it off how we want it to be. The main reason for coming here was purely to be near the children. I felt that (husband) living in (city), it, eventually if he did become unwell then. The kids found it too much, its four and a half hours. And also, our youngest son, has a disabled daughter and she can’t do 5 -6 hours in the car, so I said to him one day, ‘right we’ll just going to go back and be near the family.’ We don’t have to bother them with anything, we’re not here so they can do stuff for us, we just feel comfortable, and that’s worked out quite nicely isn’t it.

**Answer:**

we still haven’t seen them.

**Wife:**

No. We still haven’t seen them. We’re hoping next, after next

**Answer:**

She’s grown up to, to 4.

**Wife:**

Yes she’s 4

**Answer:**

And we haven’t seen them

**Wife:**

Its terrible. It’s really sad.

**Answer:**

The other thing that I was going to say about the Local Health Authority. (City name) is a beautiful place, where we lived was an absolute dream, but its miles from anywhere. To get to Hospitals I drive, (wife) doesn’t. If I’m ill we can’t get there.

**Wife:**

It was a £100 for the lady next door, her husband sadly died, and she had to go back and pick up belongings and things and it was £100 from her apartment to the Hospital and back again.

**Answer:**

And you can wait hours for an Ambulance.

**Wife:**

And imagine if you wanted to see someone every other day, or it’s quite.

**Answer:**

So, we thought, well with one thing and another, everything here’s fairly local. There’s 2 big Hospitals; plenty of good transport, which we haven’t used cos of this.

**Wife:**

I’ve got a Bus Pass and haven’t used it yet. (giggle)

**Interviewer:**

**Is it part of your planning is it just like that?**

**Wife:**

Oh yes.

**Answer:**

To be near the family, cos at least for mental support with anything else.

**Wife:**

Well I kept thinking, oh won’t have to drive, you know, won’t have the hassle. Just go out for the day on the bus, but we haven’t done that yet. (giggle) We will, we’re definitely going to do it (giggle)

**Interviewer:**

**Um, one question is how do you think the Healthcare System can be changed to try and improve, or help you manage your Parkinson’s**

**Answer:**

I think, on a personal level, probably not much different to any other level really. They’re overstretched. There’s not enough funding; there’s not enough people in the system; there’s a lot of specialities but you can get a different. If you’re in a different area you can’t access them. (name) granddaughter’s disabled. Where they live she has very good support. You move somewhere else; it could be completely different. In years gone by wherever you lived in the Country, the Health Service was the same.

**Wife:**

Do you think though what we did at the Hospital with the other partners of the people with Parkinson’s one of the biggest eye openers? I went in there, and I was listening to what they were saying, and I was thinking (husband) doesn’t do that. He doesn’t do that, and then one lady would say, ‘yes, but you’re only on the beginning of your journey. (name) has had it for 10 years’. And it was wonderful because I got to see what you’re like at 2 years; 5 years. Obviously gonna be very different, but it was wonderful to have that. and that to me was the biggest thing for us. It’s helped us, I don’t mind how many books you get or what you read, it’s it’s the interaction with people. I think if it was me, I would have a group where soon as you’re diagnosed you have this group where you go along, and 4 or 5 people and you just talk and become friends. And that is thegreatest thing of all, I think don’t you?

**Answer:**

Well, yeah well yeah. Yeah cos, it was an experience.

**Wife:**

Its wonderful. You learn so much; you know, it’s very informative.

**Answer:**

As far as the Health Service’s concerned, they’re struggling in every department, sadly.

**Wife:**

Of course, they are.

**Answer:**

Whether it will get better? Hopefully it’ll get better in the future.

**Interviewer:**

**Is there anything else you would like to add about, you know, things. The treatment, how you’ve looked after your Parkinson’s that we haven’t already talked about?**

**Answer:**

I think that up to the present point, I really haven’t got too many problems. I know I’m deteriorating, um, to what extent and how quickly I don’t know. I guess, cos I’m tremor-based Parkinson; they reckon, I’ve been told, that that is not quite so severe as other types; symptoms. So, I haven’t gone on for quite some time. Um, we did have a friend with Parkinson’s, he was 80-something, he was quite good.

**Wife:**

So there again, you learn. He used to be like this, and his wife would say, ‘now put that down’. And he’d be sitting there like doing this and she’d say, ‘stop that now’. And she had a private Consultant that she saw; she paid for. And he said to her you’ve got to make him do these things, and that’s what she did. Just a very quick thing, they used to have dinner in the evening. In the morning everything would be still there, and she’d say, ‘empty the dishwasher’. And he wouldn’t do it. And he wouldn’t do it and she’d say, ‘I’m 80 as well as you and tired’. And she made him. And this is what the Consultant said, you’ve got to pick him up. And I can see that in (husband).

**Answer:**

But mentally he’s quite sharp

**Wife:**

Yes, he was, he was.

**Answer:**

He’s still quite sharp.

**Wife:**

You have to help them I think.

**Answer:**

We attended the (city name) Parkinson’s; first session wasn’t it

**Wife:**

Oh God, that was awful.

**Answer:**

And there were 2 young girls there, I think they were in their forties, and it was just the introduction to Parkinson’s basically. And they had different people there, physios etc. And these 2 women sat there, and they were, I think they organised the actual Parkinson’s’ Groups. And we had a chat to them beforehand, and they seemed perfectly normal. As soon as they were sat in front of an audience,

**Wife:**

There were 3 of them

**Answer:**

They couldn’t control themselves

**Wife:**

There were 3 of them in a line and you can’t believe it, but the whole thing. I think that’s probably the worst thing I’ve ever been to. You got a Name Tag and you sat there, and I thought, ‘oh God, this is awful’. It was so awful.

**Answer:**

The difference between them doing a 1:1, or when you get stressed. You get anxious or stressed the tremors get worse, but in other ways you couldn’t tell.

**Wife:**

When you watch the football. Limb goes, arm goes.

**Answer:**

Anything like that.

**Wife:**

It’s quite funny.

**Interviewer:**

**And what do you think helps you manage all the things you do for your Parkinson’s. You know, the exercise, diet, medications all that stuff. What helps you manage that?**

**Answer:**

I suppose I’ve no alternative. You have to get on with it; you have to try and manage it best you. I think the fatigue’s the hardest thing, because if you’re fatigued you can’t do anything, or you feel you can’t do anything. Sometimes you have to push yourself.

**Wife:**

Do you think that’s the situation you’re in at the moment though? Once this has passed, you’ve got this finished, and the door’s in, hopefully we’re going to get the door. If that happens I think we’ll be a lot calmer in our lives and hopefully the fatigue won’t be quite as much.

**Answer:**

I think, because of Covid, we’ve been in a sedentary lifestyle. You sit around more; you’re less stimulated; less willing to do things. When I was decorating, I was doing pretty well wasn’t I?

**Wife:**

Yeah, very good

**Answer:**

Slow, very slow but I seem to be stimulated.

**Wife:**

We also had a year when, didn’t we, we packed up ready to go cos any moment one of these becomes available you gotta go, ‘yep I’ll have that’. And because of my disabilities, I decided, I said to (husband), ‘why don’t we slowly pack the house up ready and then it won’t be such a big thing’. We didn’t want to put on the children or anything. And so, we were sitting in boxes for a year. So, on top of that, you know, it sort of, its all calculated to, to sort of, you know, (yeah) the way things are a little bit isn’t it.

**Answer:**

But, um,

**Wife:**

Once we can get to see the family more, I think that’ll be, that goes naturally though, doesn’t it for everybody.

**Answer:**

I think things like, um, when I’m decorating climbing up steps, I’ve got to think what I’m doing because balance is not great. Awareness, special awareness actually is not very good at all. Um, so you’ve really got to focus on what you’re doing, you know. Cos sometimes you step back, instead of stepping back off the last step, you step off the second from last. (giggle) things like that. And when you’re up, you’ve got to hang on, you know, cos you can go anytime.

**Wife:**

And I said to you, ‘move the drill before you come down the stairs’. (giggle)

**Answer:**

Yeah, I’m always tripping over things cuz my feet don’t lift high enough.

**Wife:**

Yeah, his, his

**Answer:**

I could do with it higher up.

**Interviewer:**

**No, not that’s, I, is there anything else you think we haven’t talked about from your point of view?**

**Answer:**

I think we’ve very much covered everything.

**Wife:**

Yeah (yeah). I think the biggest thing for me is for him. Which is very important, but also important for people when they first get it, that is so so important.

**Answer:**

If I can read me writing, so small. I think I’ve been through it. Err, lightheaded, puzzles, memory, tripping, dexterity, fatigue, cramps, cognition. Yeah, I’m not very well co-ordinated either but I don’t think that’s anything to do with Parkinson’s. Apparently, I can’t dance.

**Interviewer:**

**Thank you very much.**