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| * PD for 11 years * PhD at age 60, “activist” * Financial capacity and high education levels * Feels like HCPs need to see her at her best by cycling into appointments |

**Interviewer:**

**So, I would just like to start really by asking some generic questions about your Parkinson’s. Tell me how long you’ve been diagnosed with Parkinson’s and how did that come about?**

**Answer:**

Right. Well, I was diagnosed in October 2010. And it came about, principally, because on my bicycle, which you can imagine is a traditional bike with block handlebars. I was finding that I couldn’t, um, it wasn’t only falling over but I couldn’t keep it on the side of the road that it’s supposed to be on. I kept moving out to the centre of the road. And when I started off on a bike, the junction after stopping, say a T junction, it was difficult to get started again. And I didn’t know what was going on, and it was that which prompted me to ask questions about what was going on. And difficulties with the bicycle I can’t track back at least to 2005, possibly even earlier because, after I was diagnosed, I realised that a whole lot of other things that I was experiencing was probably down to the same reason.

**Interviewer:**

**And who did you see first about your symptoms?**

**Answer:**

(Neurology Consultant)

**Interviewer:**

**Is that your local GP?**

**Answer:**

No, he’s a, a Consultant.

**Interviewer:**

**And it was referred from your GP to see the Consultant or?**

**Answer:**

Yes. Err, yes, yes. I had a, problems with my left, I’m left-handed. I had problems with my left arm which, um, resulted in 2 operations on my left elbow. One for Ulnar Nerve, earlier one for a broken bone; my elbow was chipped off at the end. And, um, the Consultant that did the Ulnar Nerve operation, (Orthopaedic Consultant). I think he’s quite high up in your (hospital)

**Interviewer:**

**Yes, hand surgeon, yes.**

**Answer:**

He was the first person that mentioned Parkinson’s. But because, and that was 2 years or 3 years earlier when it was diagnosed, but because I didn’t know what it was, and I didn’t have any other idea that that’s what might be causing it. And he was actually consulting about a different issue; I didn’t pay any attention. So, I think I’ve had it for quite a long time. So, if people often ask me how long I’ve had it for, I’ll say about 15,16 years I think.

**Interviewer:**

**And how did you find getting information about Parkinson’s**

**Answer:**

Um, well, pretty easy actually. Um, but I think I went through a phase, like most people go through, when they’re diagnosed with something not very nice, is that you find out as much as you can. You read up a lot of stuff on the internet, through Parkinson’s UK, and then you think, ‘oh hang on a minute, I don’t want to get sunk into this stuff’. So, I don’t really do much on that way now.

**Interviewer:**

**So, you chose not to search**

**Answer:**

Chose not to, yes.

**Interviewer:**

**Um, and if you ever had a question, or a concern, about your Parkinson’s you look it up yourself. Or would you prefer to ask someone?**

**Answer:**

I generally look it up myself. But I generally don’t need to do anything about it because, I’ve a fair idea about what might happen to me Parkinson’s wise so I can generally tell whether something is or isn’t. and if I’m not sure, I don’t really bother to know, I get on with my life.

**Interviewer:**

**And how are you at finding information online. Do you think it’s easy or difficult understanding the information that’s on there?**

**Answer:**

It’s easy.

**Interviewer:**

**And, um, other than your Parkinson’s do you have any other medical conditions?**

**Answer:**

Oh yeah (giggle). Um, horrible thought am turning into a person with, elderly person with complexing needs as the saying goes. Um, I, um, have high blood pressure but it’s not actually, it’s, its um. I take one small tablet a day, low dosage, Amlodipine, but it tends to give me very low pressure in the morning and high pressure in the evening. And, um, the pressure is too low in the morning, makes me feel sick actually, but, if I don’t take it for, which I didn’t recently with the agreement of (PD specialist); stop taking it for a month; haven’t told her this yet.

So, she knew I was going to stop taking it for a month, but I haven’t told her the result. I was recording the results of blood pressure every evening, round about the middle of the evening between 7 and 11 at night. And I thought it was a bit high, so I started taking it again to, and then, reverted back to the getting it too low in the morning; feeling sick, and having to put up with that, and then finding it too high in the evening and alright during the day.

**Interviewer:**

**And how do you, how do you find monitoring your blood pressure?**

**Answer:**

Bloody nuisance. It’s a nuisance because it always takes me ages to get ready in the morning for whatever I’m doing. So, normally I don’t do it every day. If I want to record it, like a morning and evening, which is what *(PD Specialist)* asked me to for a week once I decided to start taking the tablets again. Then, I just think to myself, ‘oh, shit, I’ve got to, I’ve got to remember to do it in the morning and the evening’. And because I don’t lead a very routine sort of existence, it was not, it’s not necessarily the same. It could be, um, 9 o’clock one morning and midday the next morning. And it could be 5 o’clock one afternoon and midnight the next day, so it’s not even.

**Interviewer:**

**And, yeah, you said mornings are a bit slow for you, is that because of your Parkinson’s?**

**Answer:**

Yes

**Interviewer:**

**And how has that been over the years, how have you managed that with the mornings?**

**Answer:**

You just do. Um, so like, getting dressed takes a while, too long. It just takes, it just takes a long time. So, in the mornings I’ll normally have a shower; getting dry once I’ve had a. A shower doesn’t take a long time, any more than usual, but um, getting dry takes a long time because it’s using my hands. They don’t work in the way they used to. Getting dressed takes a long time; getting breakfast takes a long time; eating it takes a long time; washing it up and clearing it up takes a long time, yeah.

**Interviewer:**

**And other than your blood pressure, any other medical conditions?**

**Answer:**

Um, at the moment I’ve got a rash, which I’ve had for a few weeks, not quite sure, it’s all over me kind of thing. It doesn’t bother me during the day, at night it gets itchy. I’m taking anti-histamine tablets which is what the Doctor recommended but you can’t carry on taking them for weeks on end. So, when I write to the GP about my blood pressure, I’ll also say, um, about the rash, that I’ve still got it.

And also, I got a Urinary Tract Infection recently, which was coupled with getting Cystitis lots of times over the last 2 or 3 years. And she’s given me Vagifem to use, and she said to use it 5 nights a week which I’m concerned about, cos I was using it twice a week. And if you read the bits of paper inside the packet, it links it with the possibility of strokes. And since I, and it says quite specifically if you’ve ever had a blood clot, which I have had in my leg after I had a bunion operation, admittedly 20 years ago. And I have high blood pressure, which it also says, ‘if you have high blood pressure or ever had a blood clot then don’t take these tablets’. I don’t really want to have doubled my taking them from twice a week to 5 times a week, so I need to write to her about that too.

But nowadays, as you know, it’s quite difficult getting in touch, it’s much easier if I could just pick up the phone and talk to a Doctor. But you can’t do that anymore.

**Interviewer:**

**And how have you found that change in talking to your GP or?**

**Answer:**

Hate it. I used to have a GP, (GP name), she’s retired. She retired about 3 years ago. And when she was my GP, which she was for about 20 years, she got to know me; I got to know her, and she was a person I went to see. I’d phone up and say, ‘you know, I want an appointment with (GP name)’, and they’d make an appointment with (GP name), Nowadays, there’s no one Doctor, I, that knows me. I don’t like that. And I’m sure I’m not unusual in that situation.

**Interviewer:**

**And have you had any telephone appointments or (yeah). and how have you found those?**

**Answer:**

Well, agh, I, my gut feeling is that people who have chronic illnesses like me, whether it’s, it doesn’t have to be Parkinson’s, but probably MS or something else chronic, we ought to be put in a separate category and given easier access. Because quite often what we want to talk about is not just one thing. Um, so I think if you going to want to talk about one thing.

And the other thing I missed out is that I’ve got Blepharitis which means that my eyes water a lot, and it’s kind of oily. Because it’s, um, stuff on the inside of my glasses and I can’t see very well. I’m forever taking them off and wiping them.

So, I would like it if people with complex needs could be given an easier route to see a GP more regularly. If I just want to ring up about, well I don’t just want to ring up about something simple, because you can find out what you want to find out something simple on the internet. You don’t have to bother the Doctor about it.

**Interviewer:**

**And do you ever talk to your GP about your Parkinson’s specifically or is it about other things**

**Answer:**

No, I don’t. For example, I went to see, I know as you said I’ve got Parkinson’s in case they haven’t noticed cos they. And nowadays they’re so busy, I can’t rely on the fact that they’re read anything in my file whatsoever, and have any idea of the history, my history. So, err, a few months ago, I, um, hurt my knee and I couldn’t do my exercises that meant using my knees because I. it was the right one actually. I did an exercise and pulled it a bit too much; I didn’t do the exercise quite the way that Andy, who’s my trainer, suggested I should. I cheated a bit, and it went ‘ping’.

And I went to see a Doctor about that, and, they actually. Now on that occasion it worked out alright because I just filled in the form electronically, and they contacted me and said I had to come in for a face-to-face because actually he had to see how the knee was. He couldn’t do that over the telephone. So that kind of, um, how can I put it, um, self-contained problem, health problem is quite reasonable to be dealt with under the new systems.

**Interviewer:**

**So, did you say you had to use the e-consult, the online**

**Answer:**

I have used it. I don’t like using it because I’d much rather. I don’t like using because it takes about 20 minutes to half-an-hour to fill it out. And, because I’m very slow and I keep on hitting the wrong button because I’m shaking, so, it’s a nuisance to use it. It would be much easier for me if I could just send an e-mail in saying, ‘this is what I want to see the Doctor about’. Cos the way the e-consult is constructed it’s in silos; something on your skin or there’s something on your bones or there’s something wrong with something else. It doesn’t allow you to say there’s, ‘deal with yourself as a, um, homeopathic person, all in one’. It doesn’t allow you to do that. whereas if I was going to compose an e-mail, I’d put it in the round. But on the system we’ve got with Abbeywell Surgery, which is the one I’m tied to, it doesn’t allow you to do that. Because there is a provision on the e-consult system they’ve bought to do that, but it’s not operative so they must have made a decision to not use it. Cos if you click on its message, it just says, ‘service not available’.

**Interviewer:**

**And I suppose when you’ve mentioned writing to your GP about your blood pressure and the rash. Is that though e-mail or do you?**

**Answer:**

I’m going to write her a letter cos that way I can get round the system.

**Interviewer:**

**Yes, yes. And is that what you’ve done before?**

**Answer:**

Yes.

**Interviewer:**

**Yes. And does that work?**

**Answer:**

Yes.

**Interviewer:**

**And she gets hold of you after that does she?**

**Answer:**

Well, it’s quite a long time since I wrote a letter. Um, so, in the past then yes it’s been resolved.

**Interviewer:**

**Good, okay. And, yes, just thinking about, I suppose, you know, your Parkinson’s and what you do for your Parkinson’s. Has that had an impact on, on your life or social networks?**

**Answer:**

Yes.

**Interviewer:**

**In what way?**

**Answer:**

They’ve narrowed.

**Interviewer:**

**In what way have you experienced that for example?**

**Answer:**

Um, well, just thinking one example. Um, in the early stages of the Parkinson’s diagnosis I just carried on doing what I was doing. So, if I was to get an e-mail from, for example, (London University) which is where I did my Degree. I did all my academic work, as an adult, an old adult, finished my PhD when I was nearly 60, so bear that in mind.

Um, say I got an e-mail from (London University) saying there’s a Lecture about such and such, in London, I wouldn’t think twice about hopping on a train; driving to (city); parking the car; popping on the train; going up to London for the evening. And getting the tube and coming back.

I don’t think I’d like to do that now because I think I wouldn’t feel safe. In case I got knocked over, physically knocked over on (London train station). Having said that, a friend of mine that lives in London, (name), I just got a WhatsApp from her this morning saying um, ‘can we meet up; are you able to come up to town on the 15th of November?’ And I’d already said to her that if I went up to London I’d quite like to go to the V&A and look at the costume collection.

But again, I’m not sure how I’d cope with it now. Like, a few years ago we went up to London, me and (name), for one of the, um, exhibitions, bit exhibitions at the British Museum. Um, actually, one of the Japanese artists, Oki, and err, it was very crowded, and it was hard for me to actually go round the exhibition. It was very, very tiring but I’m glad I went, but I’m not sure I’d want to do it now. So, in those kind of ways, I feel that my, um, world has narrowed somewhat.

**Interviewer:**

**And do you feel overstretched with what you have to do to look after your Parkinson’s?**

**Answer:**

Yes, sometimes.

**Interviewer:**

**And try to explain that or describe that to me if you can?**

**Answer:**

Um, hold on a minute I’ll get my diary and that will explain it. I’ll process it by saying why’s my Hairdresser last Friday and she said, ‘doing anything interesting this week-end (name)? and I said, ‘I hope not’ (giggle). But this week is a lightweight week.

So, I went to see Andy, that’s my fitness trainer on Tuesday; didn’t have anything on Monday. But I took the Mini out to practice parking it. Tuesday I went to see Andy, my exercises take more or less two and a half hours. Yesterday night I had an Executive Meeting, 7.30 till about 8.30 – 9 o’clock. Then you’re coming; tomorrow, Friday I haven’t got anything particular so that’s a lightweight week.

If we go back to, this is just any old week okay. September the 27th – 2 of the British Cycling Local Leaders that I’m part of; I lead rides from (town) for British Cycling. Coming out of my house at 2 o’clock to discuss, err, hand-out of different routes that I’m familiar with, they might want to make use of that’s Monday. Tuesday, 12.30 I’m going to have my back manip, my back manipulated, and various. And then I’ve got my brother and his partner and her sister phoning me for a conversation about a new flat they’re moving into. And at 2.15pm I went to see (GP name) about various things. Then on the Wednesday the 29th, nothing. Thursday, I took a ride out to near (city), 18 miles. Friday, um, and I did some exercise in the morning before I left for the cycle ride. And Friday I was free. And so, it goes on.

And I just feel I can’t deal with this, you know, I just need more, more time when I’ve got bugger all to do, excuse my language. I don’t know if that sounds busy to you, but, another week, I’m, I used to be even busier than that (yes). I’ve still got a pretty heavyweight diary. And although they’re lightweight things like needing a ride or meeting a couple of people locally about organising cycle rides, they’re not quite the same level if you like, as I did. But they still take a lot of energy out of me. As this will as well.

**Interviewer:**

**And how do you manage your medications with Parkinson’s, around all of that?**

**Answer:**

Um. When I get up I take my first Madopar. And I have bought this little sweetie, all this a few years ago. And if I’m going out (oh yes), so I put one in there, but I don’t put more than one.

**Interviewer:**

**How many times, so you just take Madopar for your**

**Answer:**

I take, this is 50 milligrams, Madopar. Well in the morning, I take it 4 times a day. And, um, actually it was interesting in that I thought (PD specialist), the last time I saw a (PD specialist), it was the first time I’d a session with her because the previous occasion was with (PD specialist 2). (PD specialist) wanted me to tell her what time I was going to take the tablets, that presumes that I got up the same time every morning. Well, my life isn’t like that. So, I might get up at 8 o’clock, don’t usually get up earlier than 8 o’clock; I might get up at quarter to ten. So, the times that I take the tablets during the day will vary quite a bit.

**Interviewer:**

**Do you space them out at all?**

**Answer:**

Yes, I take them every 4 hours basically; 4 times a day. I take so, I take this when I get up in the morning, I’ll take it 3 other times in the day, so that’s 4 times whilst I’m up. And I’ll take the Madopar, um, prolonged release, 100 grams and I take at night, that’s it.

**Interviewer:**

**And then the Amlodipine you take for your blood pressure?**

**Answer:**

Yes

**Interviewer:**

**Any other medications that you take?**

**Answer:**

Um, yeah. I take Laxido, but, I am, the, um, amount. That’s because, as you know, constipation is frequently associated with Parkinson’s. And, um, the, err, specified dosage is um, 1 packet a day. I actually take one packet over 3 days, so I take a lot less than what is recommended. Then I also take 2 over the counter, don’t know how well you know (town) there’s a shop called (shop name), (um, oh yes) it’s a Health Food Shop (the Health Food shop, yes, yes), that I get from them.

**Interviewer:**

**It’s just natural, natural**

**Answer:**

One of them is a, an, a natural husk which swell up so it’s really extreme roughage, I’d put it. And it’s got probiotics in it. And the other one is called Inulin, which is also a natural product. It’s got pri, prebiotics in it. So, I take those two during the day, in water.

**Interviewer:**

**Okay. And, um, I suppose your 4 hours of medications, do you recognise if you need another dose of Madopar?**

**Answer:**

Well, it does actually depend what I’m doing a bit. If I’m out on the bike, the trike, I often don’t think about it, and then I can get up if I’ve finished a ride, we’ve got, we’ve arrived somewhere like tea cos we normally go for tea somewhere. And I think, ah, I’m having a problem doing up the, the panier; or putting the lock on, ‘oh well, I haven’t taken the tablet’, that’s why I’m having a proble. So, that’s, during the, if I’m just at home during the day then yes I do notice. But also, um, I, um, might take one. Nowadays, I’m, I didn’t used to this, but nowadays I might think, ‘if I’ve got to do X like take a ride, and its only three and a half hours till the time that I leave. Instead of going to all the trouble of taking this, because I might forget about it then, I might just pop one in before I leave and that will set me up for the next 4 hours and I’ll, knowing I’ll be back in time for that. And I’ll take one just in case something happens and I’m not back, but I would actually plan taking it during the day here, rather than knowing that I’ll be, rather than be whilst I’m out. It’ll vary a bit.

**Interviewer:**

**There’s a bit of flexibility in planning around what you do (yes, yes) and when your medication times**

**Answer:**

I think a lot of people are like that aren’t they.

**Interviewer:**

**Well, I think it depends. Um, most people manage medications differently. Um, is this how you’ve always done it? Or has that been a bit of trial and error over the years that you’ve had Parkinson’s and how you’ve managed that.**

**Answer:**

No, um. Well to start with I only took it twice a day, one in the morning, once in the evening so it didn’t really arise. It’s only really arisen as I’ve gone from 3 times a day, which I was doing with (PD specialist), to 4 times a day. So, it’s relatively recent. Cos, um, (PD specialist) recommended, although we decided to abandon it, double dosage that’s 100 milligrams a pot rather than 50 milligrams a pot, and I didn’t like the jump from 50 milligrams 3 times a day to twice that. and so, we abandoned that, and I went to just 1 milligram, 1 tablet of 50 milligrams 3 times a day.

When I got to see (PD specialist), I said to her that over the summer I hadn’t really felt well, lots of the time, and I’m not really happy with the way things are. And she suggested taking the tablet 4 times a day, but only the 50 milligrams. I still feel that my excuse is that I’m small, physically very small; I don’t need 100 milligrams. 50 milligrams does alright for me, just doesn’t last long enough. It still doesn’t last long enough, it lasts about 3 hours then I start to feel that it’s having, losing effect. Um, where are we now? So, I took one at half past nine this morning, so I’ll be thinking of taking one at 1 o’clockish maybe ten past one.

**Interviewer:**

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

**Answer:**

No.

**Interviewer:**

**And any challenges with taking medications that you’ve found difficult?**

**Answer:**

Um, not with taking them, these tablets, cos they’re quite easy to swallow. I’m not that keen on taking Paracetamol when I have backache because they, um, they’re harder to swallow. But (PD specialist) suggested that I took some, err, some, some Paracetamol solution but I haven’t bothered cos I don’t like to take tablets. Only if I have backache I might go and lie upstairs in the afternoon for an hour, and that takes the backache away. I’m much more likely to do that than to take a tablet, simply because I, I really don’t like taking. Actually, it’s not just I don’t like taking tablets, I don’t, I’m not in the mental framework of thinking, ‘oh, I must take a tablet because I’ve got pain’. I just think, ‘oh I must give this a rest because I’ve got pain‘. And that’s the first thing I think about, and that’s therefore what I do. And afterwards when I get up I think, ‘oh, I suppose I could have taken a tablet’, but I don’t. Cos the next day the same thing will happen, and I’ll do the same thing; I’ll go and take a rest upstairs. And then I think, ‘well, I’m retired now, it doesn’t matter. So, if I want to take a rest upstairs, you know home, why don’t I?

**Interviewer:**

**Yes, course, yes. Um, in terms of your prescriptions, how do you get your prescriptions from the**

**Answer:**

I do them online.

**Interviewer:**

**Okay. And pick them up from the Pharmacy?**

**Answer:**

Yeah, yeah.

**Interviewer:**

**And do you find that easy or difficult?**

**Answer:**

Not particularly difficult. (husband) gets it for me quite often if he’s going into (town). Or I might take the trike down there. I only had that little mini for about 3 weeks, before that I had a white van bit like the one you saw in the (oh yes). I didn’t like to take that anywhere because I couldn’t park it, and I, the problem was alright driving it on the road, but I couldn’t park it anywhere. So, the I, (road name) is quite often quite full, so the idea of taking the van out to (road name) and then not being able to park it, put me off taking it.

**Interviewer:**

**Yes, of course. Having the mini might help with that**

**Answer:**

Yes, except it’s not working out quite so easy to drive it. It’s a Classic Car as I thought it was going to be.

**Interviewer:**

**It’s a bit harder.**

**Answer:**

Yes

**Interviewer:**

**Okay. And um, tell me about your, you know, your appointments with err, you know, with the PD Specialists and how has that been over the years. How have you found that?**

**Answer:**

I didn’t get on with (Neurologist). Err, I had a seared memory about our relationship um, because I saw him twice I think. And after the diagnosis he recommended me to go on particular tablets, um, can’t remember which ones they were, what they were called now. Para, Pramipexole

**Interviewer:**

**Pramipexole, yeah**

**Answer:**

They were the Aga, Agonist ones, the ones with the bad reputation for Narcolepsy and Obsessive-Compulsive behaviour and what have you. And um, he recommended me taking a certain amount for the first week; then double it for the second week; then triple it for the third week. And I was furios, I was absolutely furious. I was absolutely incandescent. And I phoned up, and I said err to the, his secretary, that I decided I’m not taking any of these.

And they were talking about 11 years ago now so you can see how mobile I am now, so you can imagine how much better I was then. I can still walk, go for a walk 3 or 4 miles. Only about a month earlier, from the diagnosis I’d been on an 8-mile walk. Yes it was hard, but I did it. So, I was absolutely incandescent. And his secretary said, ‘oh, (Neurologist), um, is very good about not recommending medication’. And I thought, Excuse me for saying this, but I know you’ll keep this confidential’.

I thought, “what a load of bull shit.” How could he possibly know about me and my attitude? Even though I had actually, he had taken in, hadn’t listened to what I said. Because when I was actually talking to him, he gave me the recommendation that I got Parkinson’s, I said to him at the time, ‘I don’t want to take tablets; I don’t need anything at the moment’. And he still put it in the letter. And I’ve never forgotten that. so, when I met (PD specialist), and I made it clear to (PD specialist) what I thought about (Neurologist). And she adjusted her way of dealing with me, she’d probably say quite a lot about me.

**Interviewer:**

**So, I suppose it’s important, you know, as part, what you’re saying is, you know, listening to what your views and, well, your own body’s experiences of Parkinson’s is important.**

**Answer:**

Well, I’m. some people, somebody said to me a couple of weeks ago that when they first met me, they thought I was formidable so, um, I clearly give that message out when I’m meeting people.

**Interviewer:**

**And do you ever see the PD Nurse Specialist, Parkinson’s?**

**Answer:**

I’ve never met her.

**Interviewer:**

**Okay, yeah. I suppose you haven’t needed to or?**

**Answer:**

Well, I don’t really think I need to. As far as I’m concerned it’s just one more bloody visit to medics of some sort. You know, by the time you’ve gone to the Dentist, Opticians, Consultants for, I also get Consultants for my eyes. I’ve got an appointment, and I’ve got to go and see the Doctor about this, see this, it’s probably Skin Cancer. So, I’ve got to go and see a Dermatologist about that on the 1st November. Um, and then I go and see Andy every fortnight; I go to the hairdressers once a month. It’s nearly always something on that means I have to go out and spend time doing stuff, when I might just like to finish reading my book from the Library.

**Interviewer:**

**So, do you see any other, so you’ve got your Personal Trainer. And have you ever seen, needed to see an Occupational Therapist or Speech Therapist, it’s mainly the PD Specialist, your GP, and your Personal Trainer for your**

**Answer:**

No. Though I recognise, I always was a very articulate speaker and I’m not as good as I was.

**Interviewer:**

**And do you think that’s had an effect on, on your appointments and your health**

**Answer:**

No, it hasn’t had an effect on my appointments or my health, but it has had an effect of what I offer to do for (political party)

**Interviewer:**

**Um, yeah. And do you think Parkinson’s has been the main, well the main effect of that with your speech**

**Answer:**

Well yes. For example, um, shortly after I was diagnosed, would have been about 2 years afterwards, I organised a session for the (political party). You know the TV Programme, Question Time, I organised a Question Time, and had 4, panel of 4 or 5 speakers. And I was the host, so I did the, what, what Maitland does, and I couldn’t do it now, but I did it then. I was good at it actually, we had a good showing. But I can’t offer to do things like that, and I can’t really offer to hand out. I have actually, in the last year, gone to hand out leaflets. I did, for the election not last year, but the General Election in 2019; issued 50 odd, 100 leaflets around (town). But I begin to find, begin to find that doing this. You’ve got leaflets in one hand and then the other hand you take the leaflet and put it in the letter box. And some people’s approach to the letter boxes was up steep stairs; downstairs; or slippery without anything to hold on to, so I’m not doing that anymore, you know. So, in those ways, my activities, err, slimmed down.

**Interviewer:**

**Yes, of course. And um, have you ever needed to get help, you know, at the weekends or overnight?**

**Answer:**

I have fainted a few times. This is due to the low blood pressure. What tends to happen is a combination of doing a lot of exercise, in one way or another, not necessarily on the bike, but it might have been on the bike; getting overly hungry; then eating a big meal and blood coming down; passing out I hit the kitchen floor on one occasion when there wasn’t anybody here. (husband) was looking after his Auntie who was dying in Bath, and I was on my own. And I woke up and found myself on the floor, in the kitchen (oh dear). And I phone up (husband) on his mobile; he phoned up a friend of his whose wife was a Nurse and they came round.

I**nterviewer:**

**Have you ever had to call your GP or access 111 or anything, or you can manage it yourself?**

**Answer:**

Well, I must, that’s the only time that that’s actually happened. And I’ve been on my own. The other week, well actually last week, I took a ride out to (town), we did 18 miles. We came back, and I was very tired cos I wasn’t feeling quite right when we went, and um, I had a rest for about an hour, hour and a quarter which I thought would have been enough. Then we went out for a Chinese meal, to a Chinese Restaurant in (town). And, um, I came over feeling faint; sat in the chair at the table, and I said to (name), ‘I feel as though I’m going to pass out’. And luckily there was a Paramedic sit, sat at a table next to us and he carried me to the back of the Restaurant where there was laid. I was laid down on the floor and of course the Manageress of the Restaurant dialled 999 so after a while an Ambulance turned up. So that happened last week.

**Interviewer:**

**Did you go into Hospital or?**

**Answer:**

I wouldn’t go into Hospital.

**Interviewer:**

**Why not?**

**Answer:**

I hate going to Hospital.

**Interviewer:**

**Have you had any experiences there before?**

**Answer:**

Yes. It just puts me in a really bad mood. Um, especially with something like that. I knew why, what caused it; it happened before, several times. Um, so it’s a conundrum. Do I carry on taking the Amlodipine blood pressure tablet, knowing that it stops my blood pressure going to, a bit too high in the evenings. Um, but also knowing that it, err, it’s likely to make me feel sick after breakfast and possibly pass out. So, it’s a quandary.

**Interviewer:**

**And you talked about your exercises and you showed me the videos that you follow. You’ve got a Personal Trainer. How do you find doing the exercises or keeping on top of that?**

**Answer:**

It varies. I, I do them 4 times over the fortnight. So, I saw him yester, yes Tuesday this week so I did one set on Wednesday and I’ll do another set probably Saturday or Sunday. Then I’ll do 2 the following week. So, by the time I go and see him again, I’ll have done it 4 times, so it means it’s 5 times every two week altogether if you count the session with him as well.

**Interviewer:**

**And um, how did you find out about, you know, exercise and do think that’s just**

**Answer:**

That was quite, how did I find him, or how did I find out about the need to do exercise?

**Interviewer:**

**The need to do exercise, yes.**

**Answer:**

Um, goodness.

**Interviewer:**

**Do you think, or I suppose, do you think you’re doing because of your Parkinson’s, you’re recognising that’s important or?**

**Answer:**

Um, when I was in my forties, this was way before I was diagnosed with anything, I found that I was very unfit compared to some of the people around me. I was still working at the (company) at that stage. And I thought if I didn’t do anything about it, I was going to get into a bad way by the time I was 20 years older. I also had to bear in mind that my mother, my father, both of them did nothing physically and spend a long time declining physically, err, which I hated to see them do. Neither of them had Cancer. My father did have a serious stroke when he was 49, and I really didn’t want that for me. Actually, that was probably what I was going to get, so that made me feel pretty bad about it all, the diagnosis.

So, that was one reason that drove me to start, and what I actually did at the time, so I’m talking of my forties. When I was 44 I left the (company). I went to the (London University) to do my Degree, and I did a Masters then I did a PhD. And of course, all that time, as you know, you’re more in control of how you organise your day. So, if you wanted to do your work in the evening and go out and do a bike ride in the day you can do that. And that’s what I started to do cos I always enjoyed cycling. And I joined the Club locally. And, um, got a lot fitter doing that. So, the idea of being fitter in my later age was already settled in my mind, and I guess the main influence would be what happened to my parents and my Aunt as well. they all went the same way. She spent the last 20 years of her life sitting in a chair. And I just decided that I didn’t want that for me.

**Interviewer:**

**Yeah, absolutely. And**

**Answer:**

Sorry if I’m talking too much, but I’m quite a talkative person.

**Interviewer:**

**No, that’s very helpful actually (giggle) Is there anything else. We’ve talked a bit about your medications; your appointments; exercise. Is there anything else that you do to manage your health with Parkinson’s that we haven’t already discussed?**

**Answer:**

Um, I don’t think so. I guess if I was gonna summarise it, I’d say making sure I’d got spaces sandwiched between my activity. At the same time making sure I can continue with activities and responsibilities. Um, I, I haven’t raised something which you might get a bit shocked about and it’s been my view for some time that I don’t want, and you’ll see it because of what I said about my mum and dad and my aunt. I don’t want to end my life with years of inactivity, um, just declining in a chair and then a bed which is what happened to all 3 of them. I don’t want that to happen to me. So, if they don’t come up with a cure, which it seems unlikely, I shall take myself off to Switzerland and get put down. I think that’s a perfectly legitimate thing for me to think, and that’s part of my plan. So, I’m hoping that the Legislation will change here in order for us to do that when I start to feel that’s what I want to do.

**Interviewer:**

**Yes, um, and, you know, have you, have you had any thoughts about how your care has been co-ordinated between all the different services. How has that been for you over the years?**

**Answer:**

I don’t seem to use it much. Um, I get my appointment with the Consultant, um, and mostly the conversation is around medication. And, um, I kind of think that there’s too much concentration on resolving the issues by medication rather than by any other. I think rather than by any other, um, method. And I think that if there are other methods I’ll find out about them, I don’t need a Consultant to tell me. So, for example I can’t write nowadays very easily, um, bless (PD specialist), cos she’s a lovely person. She did say to me, quite a long time ago now, to choose a fatter pencil but um, I have a beautiful fountain pen which my husband bought me when I got a place at the (London University). I use that; it’s not fat but it’s beautiful, it’s a beautiful, crafted piece of, tool, writing tool. And although I can hardly write with it, that’s bloody well what I shall use. So, I can be very stubborn, underline twice, and that probably frames my general approach.

**Interviewer:**

**And I suppose that’s part of what helps you manage your life with Parkinson’s as well do you think**

**Answer:**

I think that, um, I have a tendency to, um, tell the medics that I feel better than I do. I think, I always make an effort to turn up at the Consultant’s chair, um, opposite the Consultant that is, having come on my bicycle so, that will raise a flag to say, ‘she’s alright really’.

**Interviewer:**

**Yeah. And I suppose, do you think that’s because you don’t want more medications and you don’t want mor input or?**

**Answer:**

I think that, um, how can I put it, it’s important to me, not a very nice thing to say, to feel that I’m doing well. so, I don’t care whether I am or not doing well, I believe that I do well. And if anybody says to me I’m not doing well, I’m only doing average, and that my prescription for how to deal with my disease isn’t best for me then they can go take a jump as far as I’m concerned because it’s what I decided about me. So, I’m fiercely in control of what I do for me. And anybody that gets to know me will find that out.

**Interviewer:**

**And just thinking about, you know, how we as Healthcare System or Healthcare Professional can help you manage your Parkinson’s better. Do you have any suggestions or input of how we can help that better for you than with Parkinson’s?**

**Answer:**

No. No

**Interviewer:**

**That’s interesting, yes (giggle). It’s because I suppose Parkinson’s is different for everybody. Um, you don’t think there’s much else we can do to help you manage that.**

**Answer:**

No.

**Interviewer:**

**That’s useful. Um, is there anything else that you’d like to add that we haven’t already covered about, you know, about how you manage your Parkinson’s?**

**Answer:**

Um,, I suppose it probably useful to say I have a wonderful husband who’s up there working who nowadays does all the cooking, and most of the washing up. I, I will serve up breakfast stuff; wash it up generally speaking. And I’ll serve up my own lunch stuff and wash it up. He’ll cook the evening meal; he’s a very good cook. And more recently he’s actually clears it up as well. Um, mind you I put all the washing up that he puts in the rack away before I go to bed. So, he changes the sheets on the bed, and then we have somebody come over for a couple of hours every week to do the hoovering and things like that; to keep the bathroom. So, I do very little housework nowadays, um, that’s important. That’s very important actually. Because if I had to do more, I wouldn’t be able to do the things that I do to take me outside the house.

**Interviewer:**

**So, having those extra outside support (yeah) to help you do (yes, yes) the day-to-day things yeah. Have you had any financial expenses for your health?**

**Answer:**

We’re quite well off at the moment so, it’s not really an issue.

**Interviewer:**

**And err, um, I think that’s it for me unless there’s anything else you would like to, to mention that we haven’t talked about**

**Answer:**

Um, not about me really. I think that I’m in a favourable position financially, and because I have a stable relationship. And I do often think, what about people that are not in the position I’m in? And, um, in particular with the bicycle, tricycle, which cost a few thousand pounds. It would be so much nicer if there was some sort of National system that would support people getting something like that. And then they could get around and about a bit more.

**Interviewer:**

**Cos that’s been very important for you**

**Answer:**

That’s very important for me. Yes

**Interviewer:**

**Going to appointments you use that bicycle don’t you, you said**

**Answer:**

Well, it depends which appointments I’m going to. When I go to (hospital) to see the Dermatologist about this possible benign skin cancer, um, (husband) will take me in the car.

**Interviewer:**

**Yeah, okay. So again, having someone to take you or, having**

**Answer:**

Yes, so I don’t. There are a lot of things I have, that didn’t need to be organised for me but would have needed to be organised for me if I didn’t have them at home. And the fact that the austerity stuff nowadays means that they often probably fail to be organised for people, cos the support isn’t there; cos the money’s not there for it.

**Interviewer:**

**Yeah. That’s very important as you said for other people.**

**Answer:**

Yes

**Interviewer:**

**Who might need it?**

**Answer:**

So, I think that when people say to me, oh I’m an inspiration and all that sort of stuff; cos they do say that. well because of the fact that, especially cos of my leading them all on the bike rides, I say to them, ‘yes thank you, but I only can do this because of the fortunate situation that I’m in’.

**Interviewer:**

**Um, um, yeah yeah. that’s important, completely. I completely agree. Um, well thank you very much for that. that was very helpful.**