# Interview P01\_220621

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| * **Length of PD diagnosis – 13 years** * **11 medications, 6 different times a day (from notes, not mentioned on recording)** * **Lives alone, no carer and still drives** * **Daughters live abroad** * **Used to be ‘carer’/partner for someone with PD who died 18 months prior to interview (before COVID)** |

**Interviewer:**

***If you’re happy with what I’ve explained, id just like to start by asking some questions about your Parkinson’s. Um so how long have been diagnosed with Parkinson’s?***

**Answer:**

About 13 years.

**Interviewer:**

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

**Answer:**

I went to the Doctor with a shaking arm. I’d moved to *(town name)* after a divorce, and my mother lived with me and I always thought the shaking was stress looking after mother. But when mother died, and there was no-one to look after and I was still shaking, there was obviously another reason. So, I went to the Doctors, and saw *(PD specialist)*.

**Interviewer:**

***Okay, and how long did it take, you know, for you to get diagnosed with Parkinson’s after you’d been to the Doctors?***

**Answer:**

Oh, let me think. It, um, it was almost immediately. I went, I went to the Doctors and she said ‘I want you to go to the’, she didn’t call it the Parkinson’s or the shaking clinic, the, I cant remember what she called it. But there’s a special name that I didn’t recognise, therefore didn’t recognise it was Parkinson’s. I can’t remember what she called it now. Anyway, I went there, I think within a week I’d heard ‘please come for an appointment’. But I couldn’t because I was going to see my daughter; it was just before Christmas. Um, and then, oh I don’t know whether I can say the next bit.

***Interviewer:***

***Anything you say you know.***

**Answer:**

Well I went to see my daughter. Um, went back. Anyway, there was a Doctor there that I didn’t like, and he more or less implied ‘well what do you expect at your age, you’re going to have all these things’, you know. And so, I didn’t go for a year. That, that was, I’ve got the timing wrong. That was before I saw the Doctor and said ‘you must go to the Trembling Clinic, or something like that. that’s all a bit vague isn’t it?

**Interviewer:**

***Was this your GP the Doctor that you were saying in the first place?***

**Answer:**

No, he was a Doctor in the Practice. (*yeah)* I thought he was a very arrogant man, but he’s still there though I don’t ever go and see him.

Um, it was once I cut my leg really badly, and it bled all night cos I kept bumping into things, and I sort of drove down. You can see the state of my legs they’re very badly scarred. Um, and he said, ‘oh we can’t do that here, you’ll have to go to hospital’. I burst into tears in the middle of the Surgery *(oh dea*r), in the Waiting Room. He was not a very sympathetic Doctor I don’t think.

But anyway it would have been immediately, but of course I had that gap and I thought I’ve got to go back and that was when I, within a week, I could have gone, I had the appointment but I didn’t. I went up to see my daughter and when I came back I saw *(PD specialist)*, um one that he was training, (*Registrar)* Registrar, yes, and he came down and he was lovely. Bit I think he thought I was a bit weird, and I’ve spoken about this before. Um because my mother, with her full-blown dementia, she was potty living with me. We rubbed along together. Um, when he said, ‘I’m very sorry its Parkinson’s’, I smiled cos I thought that’s better than Dementia. (giggle) I think Parkinson’s. He was ever so sweet; he went down on his knees (okay) and held my hand. I don’t know what he thought I was going to do (giggle). But that was, that was.

But recently, in fact the Physiotherapist was here last week, I have gone down again. 13, 12 years have been a nightmare. And then January of last year, a very dear friend of mine died and I don’t know if it was co-incidental, but I think he died and I went schuh, and now there are quite a few things I can’t do. (*sorry to hear that*). That’s (*yes, it’s a big change).* Yes, yes, oh, we had our own places. He lived round the, in the road down there and we met up and did things together. Then of course it was Covid, and it’s been a real, real, knocked me for six really.

**Interviewer:**

***I think Covid’s done that for quite a lot of people.***

**Answer:**

I think so, yes, yes. So, what was the question, I probably not (giggle)

**Interviewer:**

***No that’s fine. Um, so obviously, what, once you’d had your diagnosis of Parkinson’s how did you get information about Parkinson’s or?***

**Answer:**

Oh well there’s a local Parkinson’s group which *(PD Nurse 1)* was a, the Nurse, the Parkinson’s Nurse who told me about it. So, I joined that, and I thought if I want to know everything I’ve got to be on the Committee. So, I went on the Committee, and I still belong to it, but I’m no longer on the Committee. I found it too much. Um, the Parkinson’s UK send you a magazine every quarter, and I didn’t have a computer then, I just did it, you know, by reading so, and it was sufficient for me anyway.

**Interviewer:**

***So how easy or difficult was it to get the information that you needed?***

**Answer:**

Well it was in the magazine, and then I did get a computer. I’ve got a computer now so obviously can look up whatever I want. So, the information is out there, it’s whether you want it or not. I know several people who don’t want to know, whereas I did want to know and I still want to know (of course). It’s the way you are isn’t it really?

**Interviewer:**

***And how easy or difficult was it, you know, to understand the information?***

**Answer:**

Ah, well. When we came to the, um. There were two parts of the, well there is, obviously you’ve seen the magazine, there’s two parts. A scientific bit and one for the daft people (giggle). Well I sort of read the headlines in the difficult bit, and if there was anything that alarmed me I asked my daughter to see if she knew any better cos she did a Doctorate in Biology. Um, no the A Levels, Biology, she, her research was in Cancer of the Bladder. Um, often she didn’t know so she said, ‘why don’t you just go and ask your Doctor?’

But um, I had another friend, who’s since died, who was diagnosed at the same time and she was the Administrator for a Hospital, a very clever woman, so I’d ask her as well. (giggle) And I’ve got enough information. I don’t want to know the intricacies of how it leaps across and kills brain cells and things, you know. I just want to know that’s what it does, not why.

**Interviewer:**

***And did you ever ask your Doctor anything that you didn’t understand?***

**Answer:**

My Doctor was a sweetie. She retired as well. Um, actually there’s been an awful lot of change; a new Doctor. *(PD Nurse 1)* retired in Covid, but once she said, I didn’t ask her, but she said to me, she said ‘I should go and ask your Parkinson’s Nurse she said, they know far more that we do’. And I thought ‘fair enough’ and um, towards the last 3 or 4 years before *(PD Nurse 1)* retired. I know she didn’t like to be telephoned but I typed a very bad question on the computer and she would either type it back or, um, say, ‘well you’d better come in and see me’, so that’s how, that’s how it worked. I thought it was a very good system.

Now of course we don’t one (okay), a Parkinson’s Nurse, but the Doctor that I have is a new young Doctor and she is very keen on doing, looking up things, so I think it will be alright. And they will eventually get another nurse in their group, cos *(PD nurse 2)* is covering *(town B)* isn’t she? Yes. (yes, I think so) It’s just this end of the County that we haven’t got one. I guess we could all drive to where we have to go don’t we? So

**Interviewer:**

**It sounds, was it quite easy or difficult getting in touch with your Parkinson’s Nurse if you, if you?**

**Answer:**

No, I just left a message on her, on her computer so that was very, very easy. She was very popular; she listened, and she didn’t rush you. So, if you had an appointment towards lunchtime you knew she was going to be running late (giggle). It didn’t matter to people. As far as I could see people would wait to see *(PD Nurse 1)* rather than go and see anyone else, cos none of it is life threatening as such, its just worry; you worry. (*of course)* yeah, yeah.

**Interviewer:**

***The worry can be, you know, quite significant worry if something***

**Answer.**

Yes, it is a worry and I think perhaps I’d be better off not knowing anything (giggle). I’d worry that I didn’t know anything (giggle)

**Interviewer:**

***It’s a difficult balance though, yeah.***

**Answer:**

Yes, it is sometimes yeah, yeah.

**Interviewer:**

***And you know you talked about that (PD Nurse 1) has now retired, have you noticed the difference in her absence – without a new Parkinson’s Nurse as you say?***

**Answer;**

Um, yes. Now I did see, I saw *(PD Nurse 2)* I think last time. It was fine, it was okay, but I got the impression that she was more one for delegating, but I’ve only met her the once. I’m not really sure but she said she would organise a Physiotherapist to come and see me. One came last Monday so she’s fulfilled what she said she would do. We’ll wait and see what happens with a view to going to *(local hospital A)* on a daily basis. I don’t think they can do anything about my damn shoulders but there’s lots of other things going wrong with me at the moment so (*okay)*. Perhaps they’ll sort it out I don’t know.

**Interviewer:**

***So, I suppose other than your Parkinson’s, do you have any other medical conditions? I know you talked about lots of other things.***

**Answer:**

Yes, oh well, I thought you’d like a list of my prescription.

**Interviewer:**

***Oh yes if you do have that.***

**Answer:**

Yes, I’ll go and get it because oh it’s here. I very cheekily altered the times with what, I don’t know who it was, did it for me because they didn’t suit me, so I altered them (giggle). So, I’ve written it down, here we are. So, um, heart, heart problem and I was taking a lot of, a lot of tablets, too many I had thought but what with *(PD Nurse 1)* going and (name) being poorly, and everything I never got round to asking. But when the new Doctor came along of course, it was all sorted out and I had, um, I was fainting; passing out and getting dizzy and it was because my blood pressure kept dropping because of the tablets I was taking. It was a bit of a worry because I couldn’t drive for a few weeks, but it seemed like an eternity; might have been a couple of months. (*dear*) but once it was all balanced out it doesn’t happen now, but yeah.

**Interviewer:**

***So, you’ve got heart conditions.***

**Answer:**

Um, yeah, it’s um. It’s difficult to explain to the Doctor. I don’t, in my opinion, I don’t have heart problems now, Angina or whatever they’re called it, cos I only get that if I run or do anything strenuous. Well now I can’t do anything strenuous because I’m too old and I’ve got Parkinson’s, hence I don’t have heart problems. It’s sort of a circle, sort of balancing a circle all the time (*yes it is).* So, we’ve got that one tablet now, that touch wood seems to be working. All this was just a few months ago. (*okay, yeah*) Oh and er, I’ve lost an awful lot of weight which the Doctor wanted, as I say she was young, wanted me to be tested for everything that might cause the weight loss. That’s why I was at *(local hospital A)*, and you know *(PD specialist)* waved, and did he say, ‘she might be alright for research’.

**Interviewer:**

***I think it was a suitable participant that we thought.***

**Answer:**

‘go and grab her’.

**Interviewer:**

***Yes. So, this heart problems and weight loss***

**Answer:**

Weight loss yes. I went from 9st 4lb, this morning I was 8st 2lb. it’s been over the year but what’s worrying me, and they know that I’m still worried about it, is that I can have my meals, admittedly they’re not very big meals cos I’m never hungry, but then I eat a bag of jelly babies afterwards and a chocolate easter egg and god knows what, but I don’t put the weight on. Cos I’m eating double, I feel I should be putting some weight on somewhen. I’ve got a big fat stomach but that’s – and little skinny arms, I don’t know what’s happening. The doctor and me are gradually working our way through pretty much every test there is I reckon. So, they’ll find out. But she’s rapidly coming to the conclusion, although she hasn’t said it for definite, that it’s, well I’m losing wei, not losing weight but I cannot put my weight on cos I’m worrying for the sake of worrying.

And I think she knows I’ve got a sister in; I’ve got no-one here apart from friends. My one daughter’s in Germany; the other daughter’s in Dubai; my sister-in-law, I wouldn’t put any stress on her cos she doesn’t cope very well, um, and she’s just come out of *(hospital name)* – you know what *(hospital name)* is? (no, not really) it’s a Psychiatric Unit*.* And my brother is in care. So, I thought, well there is quite a bit to worry about, you know (giggle). *(of course, yes)* so I thought, well if that’s all it is, well just get on and worry and be thankful that I’m not getting too fat (giggle). So that’s how it stands at the moment.

Um someone’s ringing me up tomorrow because, I’ve just cottoned on myself actually at this minute. Last year I was going, I wanted to be away in November, and I don’t know if you know but the GPs do the yearly tests around your birthday, makes it nice and simple doesn’t it. My birthday is in November, and I was going to be seeing my daughter and I said I don’t want, I don’t need my heart thing at all this year and of course I cancelled it. I told them well in advance. I just realised that *(GP name)* must have been reading through my notes and found that I haven’t had a heart ‘chat’ (giggle), so I’ve got it tomorrow on the telephone (giggle) *(I see*). I just cottoned on to that so.

**Interviewer:**

***And are you, of all your conditions do you think. What do you consider is your main issue at the moment with your health?***

**Answer:**

My main worry is that I’m not losing weight because I can feel a lump down here. But I have had the CT Scan, or as much as I can I think. Doctor’s just waiting for the results of the blood tests to do with protein in the blood. (*okay*) I’ve had it last week and it should be coming out soon I suppose. Um, the CT Scan, at *(local hospital B),* the Consultant said he thought it wasn’t anything to worry about. He thought it was faeces; doesn’t sound very nice does it? (giggle). I’m thinking that the lump keeps changing shape so perhaps it is faeces or perhaps it’s something little and faeces is clinging to it and getting moved on, that’s how I think. Well in that case I want to know, but I don’t know because everything’s been negative so I can only put it down to the fact that I am as my daughter says, ‘getting my knickers in a twist’. (giggle) So there we are.

**Interviewer:**

***Sounds like they, like your Doctors’, your Surgery has that in hand.***

**Answer:**

Yes, they’re very good. I’ve been here 13, 14 years and whoever I’ve seen, except for this one, they’ve, they’ve all been very good. (*that’s good)* We won’t say names or anything, but I just don’t see that one. If they say well there’s only so and so to see then I say I’ll wait, and that’s that.

**Interviewer:**

***And just thinking about your Parkinson’s. What has the impact of Parkinson’s been on your life and your social networks. What do you?***

**Answer:**

Um, socially, other than the fact that sometimes I don’t feel well enough. I play Bridge and I sometimes, not often, about three or four times kind of thing, I’ve had to let my partner down by saying ‘I really don’t feel up to coming’. Personally, I used to do a lot of painting; I used to do decorating; I used to do all sorts of things like that and now I can’t do hardly any of it. I used to do a lot of gardening but now I can only do about 10 minutes before I get back ache. Um, which I’m hoping the Physiotherapist is going to sort out.

I get very, very tired but then friends have said, ‘(name) for God’s sake, anyone your age would get tired doing that, doing what you’ve been doing’. You can’t. I don’t think deep down I’ve really accepted that there’s actually anything wrong with me. But now that I’m sort of going down I’ve had to. Um, I’ve had to.

I’ve got a cleaner that comes in now. Um, and a gardener comes, I know it sounds awful but the gardener he turns around and says ‘(name) you’ve taught me such a lot’ and I’m thinking, ‘yeah, and I’m paying £20 an hour for that’ (giggle). Young man he is, out of the mouths of babes. But I would think that’s how it’s impacted on me and I never look any different.

Um, my hair usually looks considerably better than this, but I washed it the other day. I got wet and it went all frizzy, so I thought ‘oh sod it I’m not doing it again’. (giggle) but I will do it tomorrow cos I’m going out, I will do it tomorrow morning cos I’m going out to play Bridge. So, I don’t look any different and I can be feeling like death warmed up. You can’t put a finger on it; you think ‘oh its that, it’s that, no it’s not. Let’s go and sit down’. And someone will come in and say, ‘hi (name), oh you look well’ (giggle). And I’m thinking, I could strangle someone if they, you know. That can be very irritating.

Recently, I’ve started bringing sick up; I’m not being sick; I’m feeling sick after I’ve eaten. That, at the moment, only lasts three quarters of an hour and you’re the only person I’ve told this, its only been in the last 2 or 3 weeks. Um, I hate feeling sick; I don’t know why that’s happening but anyway, they’ll find out. Um, so that’s something new.

Otherwise it’s just feeling tired, and not being able to do what I used to be ablet to do. But I suspect even if I have Parkinson’s I would still get cross with myself and I would still not accept it very readily, getting old so, I can’t really say that it. I don’t paint anymore; I don’t sew; I started off life as a Needlework teacher and I can’t even tack now. It’s, its

**Interviewer:**

***It must be very difficult.***

**Answer:**

Well, I think I sort of could manage alright. My daughters, I don’t think they have a clue, cos they’re away. But friends say, ‘you should tell them’, and er, they’ve got their lives so .. it’s been difficult because of Covid. I usually would have been over. I went over at Christmas to see (name) in Dubai. She’s the Scientist, she’s um, set up a little business writing out, um, whatever you research people, all your notes and things and doing like that. She does it from all over the world and she does charge. (*I bet)* (giggle)

But the other one in Germany, they’re on, they are actually nationalised Germans now. They live on the German Luxembourg border; she works in Luxembourg; she works for a bank. It’s a, I don’t know where I got the clever children from, I’ve been very lucky (giggle). Well, probably very difficult with having, when they’re cleverer than you, cos at one stage I was always, I was the clever one. Ex-husband was very clever as well, but now, they’ve all seemed to have overtaken me cos by the time I’ve thought of a quick reply they’re about six replies down, further down, you know. So is .. keep quiet and (daughter) was saying ‘for goodness sake mother, you look as if you’re tired out go and sit down’. Most of the stuff in the house is in German, you know, even the television is in German, well what am I supposed to do, but I, it’s very difficult.

**Interviewer:**

***And now thinking about, you know you said that you can’t do the things that you think, that you used to be able to do, (yes) what do you think stops you?***

**Answer:**

Well, the um, I cant thread a needle, cos my hands shake; if I get the needle threaded I then cant get it in the right position so that, that’s um; painting to a certain extent is me, because in the past I’ve always liked my pictures but now I seem to paint rubbish and therefore I don’t do it. Um, I did paint, done some decorating that will show, but I did paint two wicker chairs last week, white, to put in the, what was the children’s bedroom, but I’ve got rid of the bunk beds so I’ve put it back to an ordinary bed, yeah. Now the cleaner helped me move the bed and she helped me get the chairs out there, but she wasn’t around when I wanted the bring the chairs back in. So, I’ve got to put this thing on cos I keep falling.

I got the chairs as far as the steps at the back, and I thought, oh, I was exhausted and I’d only gone from one end of the garage to the other end of the garage, so because it’s undercover I left it. I thought nobody’s going to pinch the chair, they don’t want it round here. So, then the next day I did, I got it a bit further. Whereas normally I would have picked the chair up; walked it down to the bedrooms and put it in the bedroom, but everything has to be planned.

Everything has to be in stages and then, I’m, my leg’s shaking now, and if it doesn’t show I can feel it inside. Its quite a funny sensation actually, I don’t know if anyone else gets that, though I’m shaking inside. But it’s the left-hand side. What else goes wrong when I try to do something. Oh, I nearly set the bungalow on fire the other day (giggle) (*did you*). Oh, that did give me a fright. The person on this call isn’t my sister-in-law cos she wouldn’t be able to cope if there – it’s next door and they’re really sweet. The don’t bother me but they say ‘we’re here if you want us’ and there if I press that it will be next door I’ll be able to call.

Um, I’d had a bath; I’ve got one of these seat things, which half of me likes and half of me doesn’t cos you’re sitting in about that much water. Um, so I’m thinking of having a new bathroom put in but just thinking about it (giggle). It takes me a long time to make an executive decision. Um, anyway I lit the candle cos I thought ‘oh that would be better’ cos I don’t really like sitting in two inches of water and it cant be changed unless I have the water right up to the top of the bath, and that’s such a waste when we’re all trying to save water isn’t it. I can’t bring myself to do that. so, I lit the candle and about half an hour later I thought I walked through, cos the bedrooms are all through that doorway and I thought ‘that candle’s doing well. oh my God the candle’. (giggle) I blew it out which you’re not meant to cos there’s was little thing at the side to put on top to stop the oxygen. I said ‘I really must be careful’ but you’re the only person I’ve told. Cos they’ll be no names in your dissertation won’t there. (giggle) I was shaking properly after that (of course, of course) I thought oh dear, but I still like to put it on, the candle.

And I’ve got a big mirror in the bathroom I didn’t put it there; it was there when I came, and it shows everything. My spine is real classic, you know the curvature of the spine, it’s really textbook and um. I know why I went to the Doctors, originally, right at the beginning about my spine. It was on the television and they were advertising these braces; sort of supports that you could put on to pull your shoulders back. But I’d been assured by lots of people, they’re fine if you’re upright and they make your back ache something dreadful but once you take it off you’ll go like me (giggle), you sort of collapse. I didn’t bother cos they were quite expensive and rather ungainly, (giggle) so I just wear clothes that don’t, doesn’t show it (*of course*) so no.

**Interviewer:**

***So obviously thinking about your Parkinson’s, do you feel overstretched by everything that you have* *to do for your Parkinson’s – to look after your Parkinson’s?***

**Answer:**

Well let me think. I was thinking about this the other day. It’s mainly the garden. It seems to me I used to be good at everything and now I’m not good at anything. It’s um, I can see things like (name) I thought he was coming yesterday to cut the lawn. He hasn’t materialised and I’m sitting here looking at a lawn, especially at the back, that needs cutting. And when he does cut the lawn, he just cuts the lawn; he doesn’t do what I think he’s done when he does the lawn, he doesn’t do any of the edges; he doesn’t dig out a great big dandelion weed that’s sitting there, you know, so that is irritating from a Parkinson’s point of view because I can see it when I’m not physically able to do it. I have to, I sort of kneel down, … even kneel down, and then I get back ache, so I have to stand up. I go and lie down, and the back ache does go and then I think ‘oh I’m fed up with this I’m going to work through the blooming back ache and then go and lie down’. So that’s what I usually do and um, so that’s the garden.

Um, I don’t think the cleaner does very well, but she’s very, very helpful. Well actually so is the boy, you know, he’ll carry things for me; he’ll get up on the ladder and do the guttering, well that’s not his job is it so I mustn’t moan about him. It’s just he’s not a very good gardener, (giggle) even though it’s his job. But he’s a nice young lad; he’s in a band, you know, and he’s got a little girl and um, his, his family, his side of the family are German not that was much help cos I tried to learn German and I thought, I couldn’t do it. I never, I’m hopeless at languages.

Um, in fact my daughters, they must have been talking about it themselves, because um, (daughter) came to me and said um, ‘would you mind if you don’t try out your German on the children cos it’s giving them really bad accents’. And (other daughter) sort of piped up and said, ‘and please don’t try French mum because (daughter’s husband) is trying to teach the boys French (giggle). So that was that and of course they live out in the wilds in the village in Germany and there’s no-one that speaks English. And she goes to work at 7 o’clock and comes home at about 8 o’clock and her husband works in Cologne so they both work very, very hard. (*sounds like it).*  So, yes, I suppose, how can I put it.

The one thing I did try and install in my daughters was, if you want something the only way you’ll get it is by work unless you win the Lottery which is highly unlikely cos it’s one in a fourteen million chance. So, if you want it you’ve got to work for it cos your mother isn’t going to give it to you because she’s working hard as well. I worked all my life, yes, you know. (*very wise advice I think).* But I think so. Because you see, I know its parents, or grandparents like me that when the parents ‘give the child whatever they want’. (*yes indeed)* I can’t believe it, you know (*yes*).

Anyway, so, what else. I would say pretty much everything that I want to do impairs me in one way or another. Um, er, certain times for example I had my breakfast early; my prunes and custard which I don’t even like. In my opinion I very stoically go on and eat them cos they’re good for me but knowing that half an hour later I’m going to feel sick for about an hour. So, I was timing it that I wasn’t going to feel sick when you were here, and I don’t feel sick (*yeah).*

In fact, sitting here, doing nothing, I feel fine and I said that once to (daughter in Germany), she said, ‘well mum for goodness sake just sit and do nothing’. But I can’t sit and do nothing (giggle) and I’m not very good at doing .. unless I’m talking to somebody and then I can sit. But of course, I can’t have a whole series of people coming, neighbours would wonder what’s going on. But I do try and have it, so I do something every day, and I did find the isolation really bad.

Um, because my two, well I’ve got two school friends. Well I left and went all over the place, these two stayed in *(town B)* and still there so I could ring them up. Another friend was in *(town name),* but the other, but of course the two daughters were abroad. Ex-husband is up in *(city name)* and I talk to him, shows how bad the .. (giggle) isolation is, doesn’t it?

I mean we’ve always got one alright *(yeah*), sort of fundamental things that I’d be busy working; he’d be lying on the floor watching television, football and that somewhat annoyed me. But we basically grew apart. He went and worked in Saudi Arabia, and we couldn’t, and he said ‘anyway you lot would start another war before you’d been there 5 minutes’. So, otherwise we wouldn’t have drifted apart I don’t think, no. We get on alright now, and, in an emergency he would try to help but he’s not well. He’s got um, a heart, there’s something wrong with it but he can’t have the operation cos his lungs are bad. And there’s something on his lungs that needs doing but he can’t have cos his heart’s bad, so he’s just got oxygen in his room and. He doesn’t smoke anymore, he says he doesn’t regret it, he says ‘I’ve had 60 years of smoking and I enjoyed it and now I’m paying the price’, you know. And he doesn’t bother anybody. The nurse looks in on him every now and then and he watches television, football, and all that. The ex-wife rings him up, and he’ll say, ‘you alright then? What’d want?’.

**Interviewer:**

***You talked briefly about, you know, some of the things you do to help with your health. Obviously the list of medications that you have here (yeah) and seeing Doctors.***

**Answer**:

You must tell me to stop talking. No, I was a teacher, and a lifetime of talking while living on my own.

**Interviewer:**

***It is always nice to talk to someone, so very happy to listen.***

**Answer:**

You just tell me.

**Interviewer:**

***But in terms of you thinking about what you do for your health, and your Parkinson’s. So, you know, what aspects of looking after your Parkinson’s, like some of the things we’ve talked about – medications or your appointments or seeing Doctors or anything else that you can think of. You know, which aspect is particularly difficult (difficult) or challenging, or are there any*?**

**Answer;**

In a way, I guess it’s trying not to be rude to the people who say, ‘oh you look well’. that really is right up there as annoying. Um, I do almost constantly worry that I don’t have an accident, but that of course can be covered by carrying pads and what not. But it’s one more thing to have in your handbag, you know, which the normal person wouldn’t have. I don’t know, it’s not a subject that your talk a lot about is it? *(no*) that’s a worry. And, recently, because my hands have got worse, um, going out. If I go out to eat in a restaurant I don’t, I sort of miss my mouth sometimes; eating is becoming a problem now. I have to be very careful I don’t choke. Um, yes I would think that, are those ones that other people have said?

**Interviewer:**

***Yes, some people. Other people have talked, different people have different issues as you said. And do you find that your medications – how do you manage your medication?***

**Answer:**

Well, everybody’s always said, ‘oh, your medication is running down, or something’, but I hadn’t really noticed it to any great extent. You know, I’d be out in the garden, although I’m only up there for 10 minutes. In the past I’d been out in the garden and I’d think ‘I should have taken that half an hour ago’, and I’m no different. My leg is still twitching; my hands are, you know. So, I haven’t had that side of it; I don’t worry about that.

Um, its distinguishing what I feel and what is been made worse by Parkinson’s, because I’ve always had a thing about being late, I hate being late. I would, I don’t know whether you did, but I would sit down the road till the appropriate time and then come up, you know. Um, so that’s not Parkinson’s, that’s me. And this is the difficult bit distinguishing what is me and my peculiarities, to what the Parkinson’s peculiarities are (giggle), so, um, it’s never been very noticeable, my Parkinson’s. Um, I don’t feel that its noticeable now, but you’re very obviously, as an expert, you know that one leg is twitching and the other one isn’t. I can feel it but, um, and I don’t really fall over.

Um, the only time I’ve fallen flat on my face is is, I fell off that brick wall when I was trying to get to the back of the border. I can go forwards, but coming back I’m not very good at, apparently, according to Physiotherapist. I stepped back and went bang straight on the back of my head. Well that was a bit dodgy, I forgot all about my bracelet so that wasn’t much use. Um, anyway, I just lay there, came to, I didn’t pass out. That’s happened twice (*oh dear)*. But, of course, when my blood pressure kept dropping, it was happening quite a lot, um, and that was frightening but it hasn’t happened since so it doesn’t bother me. But that wasn’t much use for your question was it?

**Interviewer:**

***Oh, when you did have problems with the blood pressure, um, who did you see and how did you, manage that?***

**Answer:**

Um yes, you know, I was just thinking that. I was desperate for it to be something they could control, and get rid of rather than just Parkinson’s, cos I thought that’s me I won’t be able to drive. So, for all those weeks I was, I couldn’t get on the bus cos they’re telling you it’s Covid. This is all quite recent you see, cos of Covid. And I didn’t want to go on the bus, so I was reliant on friends to get me things, or I didn’t ask them. Next door allowed me to, you know, I sort of delegated; tins and things like that came with the Sainsbury’s van with (name) next door. Other friends I asked for light things or odd things or just one thing, and I managed. But I don’t know I’d be able to manage for any longer than I did manage, I found it quite a strain actually.

I think the whole thing that has been a strain is um, my friend dying on me. That sounds awful, but … because you know, I had someone to talk to; an aim in life; cook his dinner; cook his tea. Um, you know, I suppose he was a partner. I stayed over, you know, but he had Parkinson’s, and he couldn’t, and in the end he couldn’t swallow. Um, he, he sign, he signed basically that he didn’t mind, he didn’t want any artificial tubes or anything, you know, or resuscitation and all that, yeah. Now that’s where I got some information from, cos I was his carer partner or whatever you wanted to call me. He said ‘no, you must come with me I don’t want to do it on my own’.

Cos his sons didn’t have anything to do with him now, so we went to this end-of-life, um. (*okay)* And that was really good, we, I learnt an awful lot there. Um, that was from (city name), so most probably was somewhere that you know.

And we always said, cos we did a lot, we went on cruises and, um, I, I always want to have a go with you know. And I got him up to London on the train, cos he used to be a Railwayman. I’d come back like this (giggle). And we did all sorts of things. I, I’m really pleased he had a lovely life, I knew him about 8 years. The last 8 years of his life super I think for both of us. Um, what was I saying, um?

**Interviewer:**

***We were talking a bit about***

**Answer:**

Yes, yes we like. So, when the Consultant, it was a lady Consultant, it might have been the one that’s mentioned. Anyway, when she said ‘now, what about at the end’. ‘Oh, I don’t want to go on for ever’ he said. ‘We’re planning to do so and so next year’, can’t think, oh South Africa that’s right. Um, (giggle) and she said, ‘well’, she said ‘you do know’, and then she said ‘now would you Dr so-and-so to this, Vasc, funny name, unusual name anyway. ‘Would you explain cos you’re so much better’. And she did; words of one syllable for us, and it was excellent. And she said, ‘do you realise, if you’ve got any Neurological problem, if you are resuscitated, you will be, your resuscitation will be worse than if you didn’t have it’. Well that was obvious. ‘But if you’ve lost 50% of your brain anyway, when you’re resuscitated you’ve only got 25% whereas a normal person would have 50%’. So that was quite good. And then she said ‘basically’ she said, ‘you would be a cabbage’. And I’m sure we looked at each other and we changed our minds (giggle). So, he had already signed, well I’ve got one as well now. *(okay)*

Although looking at that footballer on television (*yes)*, there must be occasions when you’re only out for a little while, so I mentioned that to my daughter in Germany who is very blunt, and she’s very clever; everything’s black and white. She said ‘mum, by the time the ambulance has come and this, that and the other, they will all be geared up to resuscitate you and then say, ‘oh, naughty word I shouldn’t have done it, she’s got the form’. So, I wasn’t too worried cos I think by the time they find me I’ll be not worth resuscitating (*yeah*).

Though of course poor (name), was um, didn’t pass out he just couldn’t feed. If I fed him it’d go down into his lungs, the other alternative was no food just water. And when I, he was in hospital with Pneumonia, we don’t know what it was, um, and I was backwards and forwards like a yo-yo, and in the end the Hospital said ‘we cant do anything for him, please don’t send him again’, cos he just missed the lockdown for the first Covid. (*right)* He died just, I’m quite pleased actually because he would have hated it, but by then of course he was in a bed in the foetal position.

Um, I heard the Consultant, another Consultant, it wasn’t the one that I thought, said to her Registrar, ‘would you please go and talk to (name) again cos I don’t think she’s understood’. And actually, I hadn’t understood. I thought when you stopped feeding well some Pathway, or something they call it don’t they, I don’t know, um, I thought you were given Morphine and that was it in a day. He was absolutely, he was, he was hard work actually cos he was a bit of a so-and-so and he fought it right up to the end so it was for 8 days we were watching him, crying the entire time (*of course, of course).* It was hard. He was right actually I hadn’t understood.

But there we are, I shall know next time, and I’ll make you laugh, he died …… about that, and the Doctor came and certified and um, I, I was watching so I. They all went, and I went back talking to him, even though I know he couldn’t hear me. Well I was being rude to him, calling him all the names under the sun, and he suddenly moved. I, God, it was a wonder I didn’t have a heart attack actually. I ran out into the corridor screaming cos he was in a Nursing Home by then *(yeah)*, ‘you’ve got it wrong, he’s alive, you’ve got it wrong’, And this Nurse came running forward and said ‘come my dear, that’s quite normal, the dead often do that’. Well I had no idea (*no*). I knew chickens ran around with no heads on, but I didn’t know (giggle). I went oh God, I mean when you think of that it’s not surprising that I’ve gone downhill really (giggle). But it’s been quite traumatic.

**Interviewer:**

***And how did you manage your Parkinson’s while, you know, obviously looking after him, or helping to look after him. How do you manage?***

**Answer:**

You just pace it at the right time do you mean? (*yeah well*) if it was the wrong time I thought ‘blow it’ and I just took them. Um

**Interviewer:**

***Is this your medications?***

**Answer:**

Yeah. medication, yes. I didn’t bother with it cos *(okay*) (name) came first. And it was quite quick really. that last week was drawn out I think, um, mainly I think, I can’t, I’d have to look it up to know how many days it was. Mainly cos I think he was a popular fella, that’s him there and there, that’s 85th birthday; cos he was 10 years older than me. And all those flowers are from my garden.

**Interviewer:**

***Oh, wow, amazing, yes.***

**Answer;**

I had about 10 tables with bunches of roses on them. (*amazing)* Oh well anyway I di … Um, so he was a very popular fella then. He smiled, he always smiled. I used to say to him ‘you look daft smiling, what you smiling about’. Oh, he just said ‘I’m happy, you know because I’ve got you’. ‘You stupid thing, go away, don’t start that again’.

**Interviewer:**

***It sounds like your medications you just took it***

**Answer:**

I took it when I remembered it. Which did nearly lead me to believe that perhaps I didn’t have Parkinson’s. Now I know I’ve got it cos of the, the other things so I can cope with that.

**Interviewer:**

***So, do you ..***

**Answer:**

The worst part of that, well in the end, um, it wasn’t. it was right at the beginning; it was there 18 months. We had a room that was a double room; I don’t think some of the staff liked it cos we weren’t married and um, he, he paid for it and that was that. Um, because I think the staff didn’t like it cos I turned up at odd hours and I had a key. I had one of those pass keys. The office said, ‘we never know when you’re coming, take this’. So, I’d go in half past ten, he’d still be in his pyjamas or they’d put him in pull up things which, he was a very smart man and he wouldn’t have liked it. I just know he wouldn’t have liked it. And they said ‘how d’you know?’

Well I said, ‘well he was the least sporty person, all he could was swim and he used to teach Water Polo, as a side-line’. That’s another story. Um, I know he would want to look nice, so in a way, my daughters always say, you sail through life mummy happy ignorance too. You haven’t a clue half the time what’s going on, and I think ‘well, no I don’t, I think I’m quite on the ball’. (giggle) you know.

So that was fine, so when he was in the bungalow, it’s a bit of a long story, he did have a wife and he did have two boys. I has, um, which I have since seen and he’s alright, but he irritates me. He’s got Bipolar and he tries to show off and I think ‘you’re just making yourself look daft because, you know, you’re not very bright. And the other one’s got Schizophrenia and has taken himself off to a Psychiatric Unit somewhere down in Cornwall. So, he had no-one except a nephew and niece, and when he (name), died, he just wanted it all done.

Nonsense sorted out. So, I took myself off to Dubai, nobody can say I’ve taken anything from this bungalow cos I wasn’t here, you know. When I came back it was all done and dusted; the bungalow was sold. They virtually gave it away. But, no, I mean, no good to him so, (*no*) the son well he had about £400k, so I think that’s enough for anybody isn’t it? (giggle) (*coming back)* oh I’m sorry.

**Interviewer:**

***No, please don’t worry. Just thinking obviously, thinking about your Parkinson’s, and focusing a bit more on that (yes cos you). What do you do if you have a concern or question about your Parkinson’s?***

**Answer;**

If I had. Well, I would have gone to *(PD Nurse 1)* but she’s not there now. So now, I would go to *(GP name)*, I would go to my GP because my, the GP that was at the Surgery when I first moved into the bungalow she was lovely, *(previous GP)*, but she retired. And then I had whole series of Doctors because ‘I don’t want to see him’, ‘oh well you can’t see so-and-so and so’. Anyway, *(GP name)* arrived, and I thought she was nice; bright young face; latest things, you know, like yourself. Um, so I would go and see her. In fact, I did book to see her, but I in actual fact saw another Doctor who was equally as young, a male Doctor, and he said ‘oh, are you worried about …’ And I don’t know what you call it when they see it, see lumps in your Colon

**Interviewer:**

***Oh, Colonoscopy.***

**Answer;**

With the hand, you know. ‘Do you want a Nurse in with you?’ ‘well no get on with it’. You know. After that I saw *(GP name)*, so I would go to the GP but prior to that I would have gone to the Parkinson’s Nurse. (*yeah, yeah)* Because I think I suspect what *(GP name)* doesn’t know, because she hasn’t come across it, she would go and look it up cos that’s what normally happens isn’t it?

**Interviewer:**

***And how do you think your care, how well do you think your care has been co-ordinated. Obviously we talked about a few things***

**Answer:**

No, I think it’s been good. Um, it’s been fine. I, I was a bit scathing once. And I was very silly once, I shouldn’t have been scathing cos I didn’t know who was at the other end of the telephone (giggle), though I was irritated. Um, I always think that God gave me, the one thing he gave me was patience, I didn’t have it that day and I said ‘for heaven’s sake’, I said ‘how on earth are you going to take my blood pressure over the phone’. Apart from that I found it alright. *(that’s good)* I don’t know what she said, she said ‘(name) if it was necessary we would ask you to do it as I see from our notes here you have a blood pressure machine’. I said, ‘that’s if I can find it’. But definitely the Doctor, in these particular circumstances, but prior to that it would have been the Nurse, the Parkinson’s Nurse. In fact, she, she covered this area and when she walk, when I met her for the first time she came to me and she said ‘God’, she said ‘this is déjà vu’ she said, ‘my last client had this bungalow. And it was (name’), and it was really weird. She was a schoolteacher like me; she loved sewing and decorating like me; gardening like me; it was weird, it was almost as if I’d taken her place. Yes, she died and another (name) came along, that was really weird.

**Interviewer:**

***Yes. And how do you find attending all your appointments or having all these consultations. How have you found that?***

**Answer:**

Oh, you make it sound as if I’ve had a lot.

**Interviewer:**

***Well no, no.***

**Answer:**

If you take if over 13 years, um, fine, fine. Um, I always go early so I either sit in the car or if I know they’ve got magazines there I’ll sit and read the magazines. Nobody’s ever seemed to bother, you know. I quite like watching people, um, cos I don’t mind flying, you see, to my daughters’. Sit at Heathrow Airport watching people. Although people come up and talk to me, and I think ‘oh you poor soul’. (giggle) But um, yeah, that’s fine getting there.

If I didn’t have a car that would be a whole different ball game because I wouldn’t like to ask next door although they said, ‘any time’. I wouldn’t ask my sister-in-law cos the very minute she’d have to do something, I don’t want to change her into, back to how she was. She’s out of there now, you’re never likely to meet her so she wont mind me talking. You see an elegant confident woman, and you would never know that she’d been crying in the corner for hours on end, you know. And the Doctor, it was, Dr, *(PD Nurse 1)* that once told me that if that happens, cos I mean I’ve had funny 5 minutes, I think most women do. Um, it’s an imbalance; lots of chemicals and looking at I now, she was really right wasn’t she cos they were imbalanced. I think they’re balanced now, cos you know I’m okay. So, I couldn’t ask her but if I had to go by Public Transport that would be a pain. I would go by taxi and begrudge the money.

**Interviewer:**

***You sounded quite difficult when you didn’t have a car when you couldn’t drive.***

**Answer:**

Um, yes but I didn’t, yes yes, I did. It sounds silly, took me quite a while, within the last year, um. Yes, some of the time we were in lockdown, so it didn’t matter I was the same as everybody else. Um, but er, what was I going to say, that’s another thing that really annoys me having Parkinson’s. I have to say these things while I think of it, cos all of my sudden my mind will go blank and I get so cross with myself cos that’s, doesn’t normally happen as you can imagine (giggle). I don’t know, you know the game when you have to say, have to talk for a minute without repeating yourself (*yes),* party game. I found that one very easy (giggle) (*very good).* So, when I played I could do. (*yes, yes)* So that’s another thing, oh we’re getting there. You must have about 5 or 6 by now.

**Interviewer:**

***Yes, yeah, well, but I suppose in terms of, you know, when you couldn’t drive and you said you didn’t want to ask people for help (yes), what did you do, you know, to try and manage it otherwise?***

**Answer:**

Um, well I, I gave. People that offered I had to say ‘oh, I’m really out of a bag of potatoes,’ and I’d give them two or three things instead of the full shop. (*yeah, I see yeah*) but that’s, cos I couldn’t eat, and of course we’ve got the Spar up the road. That’s why these bungalows are so popular; round the corner we’ve got a Post Office and Spar and a hairdresser. We’ve still got to walk up the hill, I find that hard but, um, I find.

I was going to ask the Physiotherapist, when I’ve got a walking stick, um, I can’t manage so well. I need another hand, I, I just cant manage it and it, so I don’t take a walking stick with me I leave it in the car because I, I tried not to go in the Disabled Badge place, but once I did in B&Q, almost 6 years ago now and I saw um, oh no it was longer ago than that, um, I saw a nice bird table and I thought that’ll look nice in the garden and I picked up the box, ‘oh its not heavy I’ll be able to manage that’. so, come out of B&Q; going to *(road name);* walking along, ‘oh my God where’s the car?’ ‘what do I do? Heart was pounding. The car was over there; the bird thingy was in my arms. Now do I leave that and hope no-one pinches it or do I stagger on to the car. I’m afraid I don’t have a very good opinion of English on the seaside, staggered onto the car. So that was difficult, but I do have a Parking Meter, except my daughters won’t park unless I take my stick. And they’re not here very often so that doesn’t happen. So, I can manage that.

**Interviewer:**

***It sounds, it sounds as if you do, you try your best to do it all yourself.***

**Answer:**

But superficially, I know it’s awful, I can manage quite well. I can put on a good show, and then in the middle of the night, I have to stop crying, I mean, I think ‘oh stupid (name)’ and I’ll mess but nobody sees it. And I don’t think I would be as bad if I didn’t have Parkinson’s because you then go through the whole rigamarole.

You forget him, you them feel sorry for yourself and its not fair. My life has been a bit of a rollercoaster in that, it, my brother, my mother left my brother and I, so I was mainly. My father had Angina and worked from home cos he, he died at 48 of a heart attack. It’s been a very up and down life, in fact my brother used to say, before he got Dementia, ‘it’s a wonder we’re so normal isn’t it with what’s gone on’. (giggle) And if he ever says that now to me, which I don’t think he will, I shall burst into tears.

So, I, I put on a good show basically. Um, so I don’t know; other people most probably do the same. Um, and then I just pull myself together, I have a drink gin and orange or cocoa, whatever, or if it’s in the middle of the night, I stay up. Um, (name) didn’t have a single wrinkle on his face, and I said, ‘you haven’t got Parkin’, oh he did have Parkinson’s you haven’t got the stress that I have.

We met at a Parkinson’s Tai Chi thingy *(oh right*), this fellow came in and I, I didn’t look up and he walked across and looked at me and said, ‘is this chair taken?’ he took and the chair and I looked at him and there was a bloody great handbag sat there. How I didn’t say anything rude I do not know. ‘Good’, he said and put my handbag on the floor and sat himself down next down to me. What a bloody cheek, honestly (giggle). He had total confidence. *(yes*) so anyway he was chatting, I live at Friars Cliff which is, well I said ‘I live the other side of the road, the poor part. We just hit it off *(yeah, that’s very nice)*. I’ll come and pick you up and I said ‘oh, that’ll be nice it’ll save on petrol’. Oh God no more, he stopped driving soon after that cos he really was not a good driver.

But in connection with swimming, soon after we’d met we were staying in this Hotel. ‘oh, I’m going to just go and have a swim, I haven’t swum for ages’. I said, ‘well don’t because you won’t be able to co-ordinate yourself’. He said, ‘well you don’t know you can’t even swim’. ‘Well’ I said, ‘I read it in a magazine. Somebody had nearly drowned because they had Parkinson’s, they didn’t realise they couldn’t swim as well as they used to be able to’. About half an hour later a dead white face came in and someone had had to help him out of the, only a little indoor swimming pool, well I said I did tell you and you didn’t take any notice.

So, he was quite an obstinate man but, we had it worked out. In fact, the meals were lovely that is something I do miss, having the meals. I’d go over then, in the afternoon I’d do my own garden, I wouldn’t do his, do your own blooming garden. Though he had someone in to do his. Um, and he had a snooze in the afternoon anyway, as befitting his senior age (giggle). Um, I’d do the garden, and then I’d .. oh, I’d better go and do dinner. We’d have these Wiltshire Farm Foods, well we used to have them, and he liked them, and I added extra vegetables. And it was a big, quite a big thing. He laid the table; napkins out and it was as if we were dining every night. It was lovely really,

**Interviewer:**

***That’s been a change hasn’t it?***

**Answer:**

Yes, that’s changed. I haven’t got that. I’ve lost quite a lot since he’s been gone. I still talk to him. Um, only it’s not a problem, only now and then, don’t think I’m wallowing in. I think my daughter in Germany thinks I wallow in self-pity but um, that’s changed. I can’t think of anything else but of course as soon as you go I will think of something.

**Interviewer:**

***And you know obviously you’ve had Parkinson’s now for 13 years as you say (yes). Now, does, thinking back, perhaps thinking ahead, how do you think perhaps the healthcare system can be* *changed to help you manage your Parkinson’s better.***

**Answer:**

In this area, I think it’s most probably as good as it gets because we’ve got very qualified, um, health workers at all levels, you know, from the bottom to the top. They all seem to be very good. Um, I do know, a very dear friend of mine a school friend, um, she’s got a father-in-law that’s got Parkinson’s and he’s sees the Doctor once a year, and that is in *(county name)*. So, I suspect when you’ve got a medium amount of people everything’s fine, but when you’re at the bottom end of the scale with poor people all bundled into lots of houses, they won’t see the Doctor or anything. They found that out with Covid, didn’t they? And then at the other end of the scale, I would like to say, I don’t know, I’m really just going by the health..

**Interviewer:**

***So, have you found, what you’ve had so far?***

**Answer:**

Fine. Occasionally, I’ve had to say, ‘oh no I can’t make that, and it’s been changed’. But if its life threatening I would be able to make it. (*appointments)* Yes, appointments, sorry, yeah. So no, I, and of course I don’t what they’re doing now but there was a very active, um, social side to it if you wanted it. Um, I, I used to do the talks, not, not do the talks but organise the speakers for the monthly talk, that was my job on the Committee of the Parkinson’s, *(town A)* Parkinson’s, it was called. Um, and they all do the same. I see there’s a Parkinson’s for *(town A)*; there’s a *(town B)* Parkinson’s and there’s a *(town C)* one (*oh right*). Now that’s all within about 5 miles of each other.

So there’s all this sort of social underside going on as well, and there’s not only speakers, which I organised, um, there was Tai Chi where I met (name); dancing, but he obviously couldn’t do that cos he um, he was further down the line than me. But still went up to London.

One thing that did impact on me is um, there wasn’t a lift in one of the theatres we went to. And you know how they all come pouring out of the theatre, it, we both got a bit disorientated. I was on his left arm, must have been, and his right arm was on the rail, and his legs gave way. He sat down, and some people went ‘tut, tut, tut, fancy being drunk this early’. And he heard it, I know he did, and he just said, ‘I’m sorry’.

But it’s, it hasn’t happened .. I’ve had people tutting behind me cos I’m fumbling with money, that is a problem. Um, er, cos it’s just as difficult to get a, money out, as it is to find the card to put on the machine. And I never type in numbers in Sainsburys because the machines are too small. The Cash Point machine outside I can get the money out, and then I hand over a £20 note, or £10 note, I don’t fiddle around with coins. I get the change back and just sort of throw it in my bag and sort it out when I get back.

So, I try and speed it up as quickly as I can, but it is difficult. Not so much in Sainsburys because everything’s slowed down with Covid, but in the local Spar shop. Or I’ll go up at 8 o’clock. I go to Sainsbury’s at 7 o’clock. Me and little old men are waiting outside, there’s no-one around; no-one on the roads; I can amble round. Yeah they’re all busy avoiding me, yeah, and so, there, whatever the problem is so far as I can see, touch wood, there’s been a way of solving it. Um, there’s a whole wardrobe I can’t wear anymore, but, um, I can’t give. I don’t want to give them away, so they’ll sit there, and the kids can have them. They won’t want them obviously.

**Interviewer:**

***I’m just looking at your medication, and obviously you’ve written a list here of the times taken, how to take it. How did you, I suppose how do you manage your medications?***

**Answer:**

I take it with food if I can. Um, but I can take it with liquid, but I find it floats back up again, which is irritating. Um, so I just take one at a time with my food, swallow it down, easy peasy.

**Interviewer:**

***But obviously you have here, some on an empty stomach and some at different time.***

**Answer:**

Its um, in fact I think that something or other, I take that before I take anything else cos *(PD Nurse 1)* said it would coat my stomach and I wouldn’t feel sick. So, it could be that I need more of that now rather than the one that I’ve got.

**Interviewer.**

***So, you take medication it looks like 6 different times a day.***

**Answer:**

Oh, I’ve pushed them together. *(okay, yeah, yeah*) that was, I think it must have been the Doctor, and she was trying to be helpful by putting the times on the prescription. Cos I got it that right, oh they deliver it, that’s something else that’s helpful. Um, they, he delivered it, and I looked at the prescription in my bag and I thought ‘what is all this rubbish, I don’t take it at 8 o’clock’, you know. Well I thought someone’s changed it, either a clerk or Receptionist or something, and I thought that’s no bother I’ll just juggle them around a bit.

And the one important one, it’s important that I take Stalevo, the 3 Stalevos at the same time, and it’s important that I take one that’s meant to line my stomach, which is obviously not doing an awfully good job at the moment. And the, oh God I can’t remember what, and you know the heart one, the first one, Amidephrine, that’s the one that I must take. Once when I didn’t have some everyone jumped into action to get me some, so I came to the conclusion that was quite an important one (giggle) (*okay).*

So, one inconvenience is I’ve had to ask my Doctor, I haven’t asked *(GP name)* yet, I’ve still got one from *(PD Nurse 1)*, for an explanation as to why I’m taking a banned drug. (*okay)* And the last one Clonazepam, that, 9 o’clock I take that; 10 o’clock, depends what I’m doing. You see, cos that one calms my brain down and it helps me sleep so, not that I ever go to parties, I don’t get invited, but if I were to go to a party and it finished at 2 o’clock in the morning, I wouldn’t take the Temazepam till I finished the party (giggle). So, again it is all adaptable. This, me doing that relies on the other people not minding.

**Interviewer:**

***And by the other people you mean***

**Answer:**

Yourself; the doctor; the Parkinson’s Nurse. Um, it only needed someone to go ‘who does she think she is’, you know. You’re the experts, and you are, but also I’m an expert on my body that’s the way I look at it. (*yeah, absolutely, yeah*). So far it’s worked, until we had this problem with the lower blood pressure, and everybody did fall over themselves backwards to try and sort it out. Um, I wasn’t going to tell anybody, but it happened at friends’ houses. You know, one particular friend, my God I thought she was going to pass out. ‘Oh God’, she said, ‘oh God you’re alive’. Of course, I’m alive.

**Interviewer:**

***So, was it your Doctor, your Surgery that sorted it out in the end?***

**Answer:**

Yes, yes because, I, the Chiropodist was here, oh that’s another thing. The Chiropodist was here, and she said ‘(name), I’m another professional, I can’t let it go that you have just passed out on your stone kitchen floor’. And so, I said ‘right, I’ll go to the Doctors I promise’. I’ve known her for a long time, so I did go to the Doctors. Everybody leapt into action, but then they did say ‘well you’d better not drive until we’ve found out what’s wrong’. And I thought, aw, aw.

**Interviewer:**

***Was it easy getting in touch with your Doctor?***

**Answer:**

Um, yes I just said that, that I’ve been passing out a lot and I’ve got Parkinson’s. Oh yes, they all .. It seems to me that the National Health Service is absolutely brilliant if there’s an emergency. If there is something genuinely wrong with you, what it doesn’t have is a little room where someone that was under a lot of stress could go and have a cup of tea and just talk. They don’t have those facilities, but maybe they will after Covid. When Covid joins the flu, we’ll all be .. wont we? (giggle)

But what was the thing that I was, when I, that’s something else. I have surrounded myself with help so, although once Covid came she stopped doing my hair and I found out how to do it myself. If I sit on a chair and do this, that and the other and I’ve sorted it out. So, I did have a hairdresser; I have a gardener; I have a cleaner; I have a window cleaner; there’s one other but I can’t think what it is. Oh, delivery of tablets and delivery of meals if I want it, though I think they’re rather expensive.

Um, so that’s, that’s a lot of help and the plan is that I stay here until I literally can no longer, can’t stand up gotta crawl. And then I want to go into a Hospice; and I want to have Morphine and I want to go out on a combination of Morphine and orange, gin and orange. (giggle) I think that would be quite good. Um, that’s what I’ve told my daughters, but there’s also the bit that I haven’t shown them cos I haven’t written it out neatly yet, is that I also want to go to visit them, each of them 2 or 3 times a year. Put me in the corner; tell the kids to talk to me; oh, cos they’re not there; do what you like I want to come out cos I want some sun especially .. as I feel so much better when it’s sunny. I have never met anybody that doesn’t

**Interviewer:**

***You’ve clearly thought quite a lot about your health and what would happen in the future.***

**Answer:**

Yeah, I’ve got to do something. If it’s down to you you’ve got to do it haven’t you? Well, yeah, it is conceivable that, um, my friend in *(town name)*, she’s with a partner, he, we might have time together if you see what I mean. In each other’s houses, but she hasn’t got Parkinson’s but she’s got, what’s the thing in your ears, um, (*Tinnitus?)*, I don’t know, um, vertigo, tintilitis, *(Tinnitus probably*), I think vert, tintilitis or something (*tinnitus probably*), yes something like that (Labyrinthitis) yes, she’s got that. And a few sort of, minor things, but there’s quite a few of them so together they make quite a big hole. And, you know, I’ve known her ever since I was 13.

We could be together as it were, but to fill in times when I’m not swanning off to Dubai or um, in fact I told (daughter) the other day I don’t mind if you want to go anywhere cos I’ve seen Dubai, just make sure it’s a hot place. (giggle) So, I, there is help there. It’s my, its me that I’ve got to sort out. I don’t know how long it takes, maybe I’ll always feel sorry for myself cos, um, I taught needlework and art and I gradually did less able children, so I was working in a sub normality hospital. And then I finally landed up running a Unit for profoundly handicapped children and I took early retirement cos I got Asthma and I couldn’t do the lifting.

So, even right back then, when I was 55, there was signs that I didn’t have too good health really, something was brewing. Um, what’s that saying, don’t know, forgotten, stupid me. Yeah, no, doing what I’ve just done drives me absolutely mad, um, because I used to be relatively unparticular, and I used to, well people that know me. Our family are a shy family and the looked up and said, ‘don’t be daft, you’ll never be shy, you’re not shy’. Well I said ‘have you ever been to the theatre by yourself? Yeah of course, sat in a coffee bar by yourself, yeah’, though I hadn’t. I could no more do that. I’ve walked into a Pub and gone behind the bar and served drinks, I can do that easy peasy, but not sit in the corner with a newspaper. I just couldn’t, I never will. That and I’ve never had a pair of jeans, never worn a pair of jeans.

**Interviewer:**

***Well I suppose when it comes to asking for help if you need it with your Parkinson’s, how would***

**Answer:**

I’d have to go to the Doctor unless they had a Parkinson’s Nurse. But I do have the, um, name and telephone number of the um, secretary that co-ordinates the *(town B)* area; the *(town A)* area, so I would ring her up if I couldn’t get any help from the Surgeon, but I would go to the Surgery first I think. Because it would, it would look as if I didn’t think that she was good enough if I didn’t go there now.

I can hear my daughter saying ‘mum, you do think the stupidest of things’ (giggle). But it’s, if, so, 7 years you take to qualify and um, to call the secretary and not go to the Doctor would .., and I must admit that I don’t know what’s written on my file but I just say ‘Parkinson’s’, ‘and when would you like to come?’ In an emergency you can turn up; you’ve got to wait outside but otherwise you have to wait a week or so, but I think well I’ve had this for 13 years another fortnight wont make any difference, you know.

Yes, so, I think it’s pretty much covered, but other people I know they have been so mood about ‘oh, I couldn’t see him for another week’. I think, well do you need to see him for another week, you know. No, I think they’ve been quite good except that one that made me very upset when I was stood there dripping blood, all over his floor.

**Interviewer:**

***It’s clearly had, you know, quite a significant impact how someone, you know, talks to you, or helps you a Healthcare Professional. How they interact***

**Answer:**

I, yes, yes. Talking is, the number one thing cos I think the number one illness in our country is loneliness because we don’t have the family units. A friend of mine, another one I’ve known since I was 10, um, she’s on um, isolation now cos she’s having a knee operation in a fortnight’s time, or whatever. But, she’s never moved out of *(town B)* and she’s never had any worry or trouble. She’s been surrounded by this extended family; her mother is 101; she put her husband into care, which I didn’t agree with – that was nearly the end of a beautiful friendship, but I kept my mouth shut. And she, she just doesn’t know what life is like, she really doesn’t. She has sailed through her entire 78 years on a haze of ‘(name) will do that’ or mother again, you know.

I, it’s loneliness I think that kills in our country, it really is but oh because I mean I play Bridge; I talk to over the road. The bottom line is the two people that I want here are not here, my daughters.

Um, I’ve two grandsons, they’re at boarding school up in the north of England. I can’t get up there by myself, I wouldn’t feel safe but in desperation I would do it. I have a, oh another thing, I have a taxi to the Airport so that I don’t have to get on and off of coaches cos I can’t do it quick enough. And they fly into their little space and you all have to get off like this, I can’t do it that fast so that’s impinged on me. Oh, I’ve found a lot of things haven’t I?

**Interviewer:**

***It’s been very helpful.***

**Answer:**

You don’t know. I’d totally forgotten about that. I am going to sound like this babbling stupid woman (giggle). I’m gong to make you a cup of coffee soon.

**Interviewer:**

***No, No. Is there anything else that you’d like to add before we finish up?***

**Answer;**

No, not really because I’m now aware of something. You see I can’t work, yes I can’t work computerised things like that because believe it or not when I was working at school we had Bubble machines and this, that machine and that, and it .. someone to be in charge of all the equipment so I was just swanning around like a Queen Bee, you know. (giggle) I had to work out all the programmes and everything, you know, so I have never really got to hand with computers or anything. (name) understood. She said, ‘I think you mean this (name) don’t you?’ It’s so and so (giggle) But, um, I think I’m pretty well covered, um, only of my own making.

I’ve got friends that wouldn’t be able to do it, rely on their husbands for everything; don’t even bank, you know. Um, and, all of my own making. Hence, I know I give the impression that I don’t need help, but ‘oh she’s alright, shes’, that’s what both my daughters think I know.

Because they’re not unloving kids, I’m immensely proud of both of them. Cos the eldest one was a Solicitor before she went to Dubai, to live over there, you know, and my grandchildren, oh I haven’t even mentioned them. The two boys at Boarding School both won Rugby Scholarships to go there, that’s up North, so I’m now learning Rugby. I watch it on the television and I, I ask why, why was it a roll over whatever, so I at least know something. And my eldest granddaughter, they’re in Germany, so they took the children equivalent to the Baccalaureate, and she took 7 subjects and she got ‘A’s across the board. But they always said she was clever, but I thought the proof of it will be in what she gets. And I think 3 or 4 ‘A\*’s, my daughter couldn’t remember what it was, not taking much interest, you know. But um, and she’s now supposed, in Germany you do three years; two and a half years in sixth form and the last term you’ve got your results, you can backpack; go work in Woolworth; sit in the sun all day; do what you like, you’ve got that term free before you start your University.

What’s my eldest granddaughter, a Red Cross course that takes about three months, and as far as I know, cos I haven’t heard of if, I have to ring tonight cos I can’t last any longer. She hasn’t even found anywhere to go yet. Cos that’s what I miss, my daughters, but you can’t do anything about it. So, I can’t go and live with (daughter name) cos I don’t have enough money coming in and I can’t go to Germany because I failed dismally to learn German. I’d be even more lonely over there than I would be here because her children would have been gone by then cos all 5 of them are all very independent.

Um, and admittedly when (daughter) and (son in law), there the ones that are in Dubai, they went on a year long honeymoon backpacking. They didn’t have backpacks cos they were too old then, something else. Um, when they got to a country that I thought would be quite nice, ‘I’m coming’, so I, it was quite good. I saw quite a lot of the world, they did 9 months, they’d had enough by 9 months. She’d given in her notice and he’d, (son in law) was kept on so it was all worked out, sorry.

**Interviewer:**

***Thank you very much for that.***