# Interview with C03\_07072021

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| * Length of diagnosis 10 years * Medications 13 times a day * Has own health conditions and has delayed management to support PwP * Stopped going out and acceptance, faith and religion |

**Interviewer:**

***Um, so if you don’t mind I’ll start by asking some general questions about (wife’s) Parkinson’s. How long has she had it?***

**Answer:**

Well she’s had it diagnosed November 21, no, no, no, November 11, November 2011, 10 years. Near enough 10 years.

**Interviewer:**

***How did she get diagnosed?***

**Answer:**

She got diagnosed by (GP name), her GP, after a number of issues. Um, she, we noticed things were going wrong with her regarding things she played musically. Um, and, err, basically the, the first thing that went wrong was the flute, the arm for sure the muscles there. And she said there’s something wrong with my flute and I tried every which way to put a non-slip pad on the flute and all sorts of things too. I presume, because now knowing about saliva production, I presume she was producing more saliva and slipping a bit on it as well as the arm muscles going, just going. She had a beautiful tone on it, a lovely tone and that went.

And then um, a good friend, Doctor, was in the congregation at Church and err, noticed that (wife) was sort of staring hard at the music with a fixed, err, stare. Um, and he did come up to me and said, look I know it’s, it could be construed as being unethical but as your my friend, and, err, he said, ‘have you noticed anything wrong with (wife)?’ And my heart plummeted because I had, and err, I said, ‘yes I had’. And he said, ‘have you heard of Parkinsonism?’ that’s the first I’ve heard it referred to as Parkinsonism because I’d only heard of Parkinson’s disease. And I said, ‘yes’ and he said, I think (wife) might, might need to go to the Doctor and check it out. But she wouldn’t, we’d been, up to then she, we had discussed that she had been having problems and, um, she didn’t want to go until she had a long list of symptoms that she could reel off. Cos we need, she assumed I think, or knew that Parkinson’s was difficult to diagnose, so she had a long string of symptoms.

One of the symptoms was, her writing, her handwriting started normal and started to tail off smaller, and, and get much smaller towards the end of the line. In hindsight we know there’s classical symptoms but when you don’t know, you don’t know so. So, anyway, not long after that she went to see her GP.

Her GP, who was (GP name) at the time, before he retired, err, I don’t know if he’s retired but he’s moved away. And he was right on the ball, straightaway, and did all the things that subsequently you know that people do to test you with, you know. Touching nose to finger; and standing behind someone and just tapping them on the shoulder and see if they lose their balance and so on. So, um, he did all those things, cos she went with me, I went with her. Um, and, err, he said, right, I don’t know whether he said, ‘I think you’ve got Parkin’. I think he said, ‘you may have Parkinson’s’. Pretty sure he did, ‘but I, to confirm it I want to send you to a Specialist’. *I’ll just turn that alarm off.* ‘(Wife) your 3 o’clock alarm’s gone off’.

Um, so, so then we, we actually wanted to get in fast and so we arranged, because I worked in the NHS, for most of my working life and I knew that it would be a long time before you got called, if you went via the normal channels. So, we wanted to get the diagnosis quickly. Um, so, err, we arrange to see *(PD specialist)* privately. Um, err, and he diagnosed it straightaway. So, um, that was that. And then after, it was literally two weeks after *(PD specialist)* diagnosed it that I retired, which I was, I could go at 60 then, because the package was that you go at 60 from the NHS. Um, which was a great relief to me, cos I didn’t know how I’d, how I would cope with (wife) with Parkinson’s plus working. Um, so, that, that’s how she was diagnosed.

**Interviewer:**

***Yeah. and the choice to go private was because of the NHS waiting times you said.***

**Answer:**

Well, our assumed waiting NHS waiting time. I don’t know, I mean, knowing what we know about *(PD specialist)* and the efficiency of the Parkinson’s Team, it probably wouldn’t have been that long before we were called. But we didn’t know that. so that’s why we went privately. And then, after another year, I don’t think we got called back, and I got back to them at the Nuffield and we had another appointment, just a follow-up. Um, and then, ah, *(PD specialist)*, we did actually say, you know, we thought it was unusual not to be called back (right), and I think, bottom line, *(PD specialist) ‘s* NHS Team is so on the ball; so sharp that you don’t, you probably get, you get as good, or better than you do privately so that’s what we over to.

**Interviewer:**

***And you talk about learning about Parkinson’s and getting some information. So how did you get information about Parkinson’s?***

**Answer:**

I’m not one to go trawling the Net. We knew someone from Church who got Parkinson’s about, just before he was 40, and within 5 years he was in a wheelchair and within 10 years he was gone. Um, so, we didn’t know um, then, that err, the younger you are usually the more severe the illness, the condition is. Um, I think a lot, we joined the Parkinson’s Society, Parkinson’s UK I think it is, something like that and you get an awful lot of information then. And it’s usually balanced, good information. From the Net, you don’t, you have to sort out so much dross from the real thing I just didn’t want to go trawling the Net. And also, you can, we knew it was a deteriorative, incurable disease and so we actually prayed that it would deteriorate slowly. Um, but, at the same time, we didn’t want to cross unnecessary bridges before we came to them.

It wasn’t that we stuck our heads in the sand, it’s just, you know, we wanted to live life as free from unnecessary worry about it as we, as we could. So, I didn’t go searching but there was a lady. Er, I don’t know what her name is, is as a, she is a lady called *(Parkinson’s UK support worker)* who is, comes round and helps you with different things. Um, she helps (wife) apply for Disability um, I don’t know, Carers Allowance. Um, and also later on with her Blue Badge Application. She actually brilliant in that sort of way and she filled us in on a lot of things.

**Interviewer:**

***And she’s from the Parkinson’s UK?***

**Answer:**

She’s from the Parkinson’s UK and she’s employed by Parkinson’s UK and we have her phone number. We’ve only seen her 3 times maybe, but each time it’s been very useful. And the rest is Parkinson’s UK Magazine which you get a balanced view I think. And the other stuff is just learn on the hoof, because, we asked *(PD specialist)* what to expect and the bottom line is that no one person is the same with Parkinson’s so he couldn’t tell us exactly what to expect. So, he wasn’t going to frighten us with stuff that could happen but might not happen. So, I think that was the best way round.

I think the one bit of information we probably could have been helped with, was err, the fact that we knew that your motor, motor control goes; is compromised. But I didn’t know that the autonomic motor control also is compromised like the Intestinal Peristalsis is affected as well. it’s not as efficient. And so, it, (wife) was admitted with constipation so, it would have been helpful to know about that. And once she’d been in, and thankfully didn’t any surgery to get rid of that, and *(surgeon name)* ah, prescribed Macrogol, as a laxative. And instantly, once we’d had that we had a satisfactory solution. So, she doesn’t take it every day; she’s prescribed it and she takes it every, well (wife) is actually pretty good. She’s, every, maybe once a week; maybe twice at the worst; maybe she’ll even go longer than a week and then maybe take it a couple of days running, and that’s it then back to normal. So, she’s pretty good that way. So, have I answered that question, I’ve forgotten the answer?

**Interviewer:**

***And how was it, I suppose learning on the hoof as you would say, how’s that?***

**Answer:**

Well, I personally think it’s harder for, or just as hard if not harder for the person who, loves you and cares for you, um, to look on and feel hopeless. And not be able to do something, more. The person who’s suffering is, is suffering and that’s pretty awful; it is awful but for the Carer it is, it’s not as bad in some ways but in other ways it’s worse cos you’re always on edge. Well, not on edge but, err, I sleep like a mother with a new-born baby.

Um, so I awake the moment something, if she’s awake I wake up; I don’t know how but I do. Um, if I hear an undue sound in the house, like a thump, I will always say ‘(wife), are you okay?’ Because, usually if she has a fall there’s a pause with the shock and then, because she’s got Parkinson’s she doesn’t, hasn’t got a very loud voice so I don’t hear, ‘I’m okay’. She may have said it, but I don’t hear it so I’m shh, in, to find out if she’s alright. And if I’m in the same room. I mean, often it’s just she’s closed a drawer or a cupboard or something but, you know you’re always on the, on the lookout. And that never stops – 24 hours a day, except when you’re asleep. So, there we go, um, learning on the hoof is, well its, it’s something you have to do and, err you have to cope with.

Personally speaking, I’m thankful that we’re both Christians that we can take things to the Lord every day. Ah, and, err, you know, we’ve got a very good marriage so, we don’t have any secrets from each other. We’re pretty, I would say we’re pretty open with each other. If there’s a problem we’ll say, um, and we don’t have a, we’ve always had this thing where if there’s a problem it’s better to hit it head on than pussyfoot around. Um, I’m actually the one who bottles up more than (wife), um, err, so, she will sometimes say, ‘what’s wrong?’ And actually, I don’t know what’s wrong, but I don’t feel, I’m a bit, maybe a bit depressed or something like that about things.

Not entirely, I don’t take medication for depression but um, I do get panic attacks and I do have some emergency Diazepam for when those panic attacks were really bad. I mean I would just, I’d be soaked. And I did go through a period about 2 years ago, probably just around the time that (wife) went into Hospital 3 times in one year.

Err, and she had a bad fall in the garden and had to have a, err, a, a small operation to repair a Tendon, but she chopped herself up badly on the arms and legs. And thankfully her head, everything hit the concrete apart from the head. And she hit that sideways on so, um, there would have hit the concrete. If she’d have hit the concrete I think she probably would have been killed (oh dear), but, err, that’s probably me imagining the worst anyway. Um, so, that was probably the worst time my panic attacks have been, much much less and they’re growing much less at the moment, I don’t know why. Thank the Lord that they have been so, there we go.

Um, so, yeah I, how do I find learning .., I don’t know; I can’t describe it cos everyday something happens. I think, one other thing that it will nice as a Carer, to be, for someone to take a Carer to the side and say, ‘look, you’re going to have to, (wife) will spill things regularly every day, something will, the glass with slosh or something will go’. And that to, be constantly clearing up spillages can be really, really wearing on you. Um, constantly stopping you, you’re having a meal you have to stop eating; go and get something; sort it out and go back to your meal. That is quite, quite, it grinds you down. It’s only a tiny thing but it just grinds you down.

But there you are, you have to, it would be nice for someone to actually, I’ve never read it anywhere that um, it’s likely that a Carer, the Principal Carer, will have a huge amount of just mopping up to do. I wish they’d said that, you know. It would be so helpful. At least you’d know that goes with the territory. I know now, there we are, there we are.

**Interviewer:**

***And what other things do you help, do, help (wife) do for Parkinson’s? To help manage her health.***

**Answer:**

Err, well, she has an incontinence issue in the night. Um, because she sleeps so soundly, deeply with the Parkinson’s, um, err, this is urinary incontinence. Um, the, err, to, so we use Tena Pants and um, to prevent (wife) getting, it’s depressing waking up wet. So, to prevent that as much as we can, we know how long she can usually go and err, we will set, I will set the alarm and wake up; wake ourselves up and get her on the loo. But night times are the absolute worst because, she will, if she’s down in the very depths, I’ve learnt now it’s probably better to leave her and cope with just changing a wet pair of pants and maybe a, we use a pad underneath in case there’s a major spill. Um, and it’s better to change those when she’s awake, I mean she doesn’t really come properly to anyway, most of the time, but if I wake her and she’ll, I’ll say ‘time to go to the loo’, she’ll say, ‘okay’. And then I’ll have to help her move round on the bed.

We’ve got a really good system where she’ll bend her knees up. She is particularly going back into bed; she’ll bend her knees and sit up and I will swivel her on her bottom. Um, that, because she’s light, that’s pretty good though I have developed an Umbilical Hernia, but I don’t think that’s been from lifting (wife) I think that was um, lifting something in the garage.

I don’t think (wife) was, um, I think it was pretty good but it’s a minor Umbilical Hernia which the operation for got cancelled, um, due to Covid. Um, thinking of Mr Howell, I saw Mr Howell, cos he’s the guts man. Um, he actually said it’s very minor you could just live with it. Um, and I said, but at the time I said I’d probably be okay to have the op. so, he sorted it all out and got night cover to come in; sit up during the night, um, for a week or two. But now, she’s deteriorated a bit more so, I would put it off unless it becomes absolutely necessary now but I’ve actually got an appointment with Mr Howell in a fortnight um, just to check that it’s still okay and to let him know that. Cos I had a letter saying ‘have you missed anything; do you need to cancel the operation’ and things, and I can’t fill that in until I’ve seen him and um, let him know, ah, what, that I’ve changed my view because of (wife’s) health.

So, err, so, night times the worst; um, also when she wakes. If she’s in this deep sleep, I might wake her up, she can, sometimes, not recognise me or, not, yeah, sometimes she said, very rarely she said um, ‘where’s (husband)? And I said ‘(wife) I’m here’, and she’ll then suddenly come to and say, ‘oh yeah’. Um, but that’ll be upsetting for her. Um, or, she’ll get out of bed to the commode, to go to the commode; take two steps to the commode which is three to four steps and freeze; dead freeze. Um, so badly that she can’t properly talk to me; she can’t let go properly of things so she’s hanging on.

We have the Zimmer frame one side so that acts as a, like a barrier to hang on, and I’m hanging onto the top of the Zimmer to stabilise it. And then there’s the hand lock one side, of the, the, commode. And if she does that I’ve literally, she’ll say ‘I need to go’, err, and I will have to almost bundle her; one more step forward and turn round 90 degrees and whack down her pants and then she’s, hopefully be alright. But, that’s a, that’s really quite a, she’ll think I’m almost attacking her. Um, so, I find it easier now to just leave her and sort out the wet pants and maybe the pad depending on how much she’s gone than have her distressed with the other way round. Gonna have to go for a wee so you’ll have to pause your thing and I’ll be back in a moment.

Okay, so that’s, that’s that’s one thing. The nights are bad, and um, we get up, um a minimum of probably 3 times a night. If we get up twice, it’s very good. Um, we have had, a couple of times when it’s been twice but it’s 3, and sometimes, and I’ve no idea why this is, err. Occasionally (wife) gets shingles and round the waist, at times, it’s very mild, err, and that can affect her bladder. When that happens, it can be 5 times, 6 times in the night getting up, so that can be quite tricky. So, night times are bad.

I was at (town) car park once and when you, when you’re married to someone with Parkinson’s, you can spot someone with Parkinson’s a mile away whereas before I couldn’t tell. Now I can, and I heard, um, this poor chap he was doing his best, and his wife was really having a go at him. And I thought ‘oh dear’, but, you know, she may have had a really bad few days with him and she may just have been at the end of her tether. But she was being quite unpleasant to him. Err, and I try to resolve not to be like that.

I think, I think the endless spillages; occasionally I’ve got exasperated and that’s not right but, um, there we are, we, we have a good way. We say sorry quickly so that’s good. And err, I guess, um, as a Christian there’s a, a bit in that the Lord says about ‘if anyone wants to follow me he must take up his cross daily and follow me’. And the idea of taking up your cross in those days, was literally you were going to be executed. So, it’s a death sentence effectively so, you’d be prepared to die to self, daily and that has become very real to me since (wife) has had Parkinson’s because it’s a given that. if you don’t, if, if this happens to people who are utterly selfish, I can see it breaking up a marriage and someone just leaving the person because they can’t cope. Um, and that is a big no, no a) for Christians and b) for us.

So, it’s not easy but I’m learning how to say no to self and self rears its ugly head a lot. So, there we go. There is a good side of it is that (wife) is brilliant at, she has actually organised help around the house so that I’m freed off to have a bit more space and that’s helped enormously. So, I do, not that I’ve done it much recently, but I do watercolour painting. Ah, and, so I’ve had time when a friend who comes in and cleans, um, err, we have help – I think its 5 hours, 1, 2,3, no 1,2,3,4, - 6 hours a week we get help.

So that’s taken, mind you I’ve had to have that because I’ve got a serious neck problem, and I’ve had a back problem since 2006 but, I have got quite a serious neck problem where I’ve got to see, I’ve been to (hospital name) Spinal Rheumatology. It’s Rheumatoid Arthritis, is Rheumatoid Arthritis, but I’ve got Rheumatoid, I’ve not got Rheumatoid factor I don’t know the difference right. But I’ve got Osteoarthritis and it is, a couple of my vertebrae in my neck are basically crumbling. And this had gone very tight and, um, the CSF found this. I’m going to show you, um, yeah, get rid of those. Um, so I’ve now been referred to the Spinal Unit at (hospital name). That’s my MRI Scan (oh yes) right, which they all find fascinating I’m sure. Probably seen hundreds of people like that.

So thankfully, do, things like hoovering and things are now quite hard for me; gardening so we have a gardener as well. Um, so we pay for a gardener; we, we pay our friend to come. And so that’s helped a lot. And also, we have, recently we, since last, the lockdown last April (wife) said she stopped playing the keyboard and said, ‘can I’, well she couldn’t play like she used to so just stopped. She missed it so much I said to her, ‘why don’t you, why don’t we just take the risk and get a smaller keyboard. One that’s not weighted so it’s’.

She’s got a crack in her lunic bone in her right hand, probably it’s from an arthritic cyst but it’s probably cracked from one of her falls but um, it’s not broken, and she can use it alright. She’s on medication for, for that, um, for the, she’s got Pregabalin for that which is brilliant. Um, I, I think Pregabalin helps the shingles because it works on the nerves. I think the symptoms of the shingles are much less than before she was on Pregabalin, but that’s only my theory. Um, so she plays that with her right hand, and I play my harmonica, so we play together. So, I’ve not done quite so much art in the last year but, um, you know we do things together as much as we can. Church is brilliant. Cos these are all things that help get you through Parkinson’s.

Um, church since lockdown has been fantastic cos they already streamed, live streaming for shut-ins and so they could watch on UTube. So that got ramped up, um, so that Services on a Sunday were live streamed. I think they weren’t live streamed before; I think they were recorded and put on uTube. Um, and then, um, we had Zoom Coffee after the Morning Service so, via Zoom you go into your screen with lots of people and then you go into breakout groups which is brilliant because it stops you becoming clicky with your own friends and you get anybody who goes to Church. You just get lumped in with them for 20minutes so it’s a brilliant way of getting to know more people in Church.

Um, so that’s that and also Harmonica UK have done. I go to the Friday morning coffee, Zoom Coffee Morning just (wife) doesn’t do that. But she does, she’s been very interested in the theoretical side of things and, um, we’ve done Workshops on Saturday afternoon which has been great cos that filled a hole cos we, we, until my mum died in 2018, and on a Saturday afternoon we would always go over to Bramsgore and see her. So, there was a big hole there. And Saturday afternoon would come round, and you’d think ‘must go to mums’, and then you’d realise that mum’s gone. So, um, that’s been good. so, there’s been lots of pluses, err, particularly with, due to Covid, there’s actually been an improvement in some of the stuff we can do. Cos there’s been, there’s always been a beastly, ghastly, terrible thing there have been some positive spin-offs due to that so there we go. Any more questions I’ve rambled on enough.

**Interviewer:**

***Do you help (wife) with her medications and prescriptions?***

**Answer:**

Um, I order the prescriptions online, usually, usually I do the ordering. She sorts out which ones she wants. Um, due to the Parkinson’s sometimes something can slip the memory um, but most of the time she’s, she’s, she sorts her; puts out her pills at night. I have to open some of the pills sometimes cos the packaging, the foil packaging in some of the tiny pills is so small that for someone with finger problems, with Parkinson’s, it’s really difficult to get them out. She can do it at a push, but I do help from time to time. And usually first thing in the morning when she’s woken up, she’s got very little Dopamine inside her.

I forgot to say, at night is she does freeze, we’ve got this emergency, um, dispersible Madopar tablet. She has found that, recently, only in the last month or so that if you suck it up with a straw because it settles down because it’s dispersible, not soluble, um, if you take it with a straw, um, you get the most from that sinks down the bottom anyway. So that’s been good. So, if she has that, the next day, it varies, sometimes she’ll have more dyskinesia.

Um, but, other days she’ll be almost normal. She’ll be really good which are not as often as we like but, you know, when they come they’re a great surprise and joy, when you’ve got a normal day. So, um, so with the tablets I obviously get that out cos she’s frozen at night. Um, so that one is definitely my bag, the rest of the time it’s mostly her bag. Um, she lets me order it online um, but she could do it herself. Um, depends how bad a day she’s having to be honest, cos some days the mental effort of getting stuff done is really hard.

And it’s another thing with Parkinson’s is that what, a thought process that we would normally be dead easy, takes effort; actually, exhausts you and depletes your Dopamine so you get worse. And I’ve found that if she watches, she loves tennis, um, so if she watches the tennis. It’s a really, really exciting match, she’ll be, Parkinson’s wise, she’ll be done in at the end of it because she’s, I think, I don’t know what it is but it might use up Dopamine just being really in with it; playing the points with them on the box. So, um, so I do help, but if I, for example, if I have an emergency with my neck or something, its’ a toss-up as to whether (wife) would need to go into a Nursing Home for the period I am recuperating. Or whether, I think, and actually, um, other Healthcare Professionals like, we have a Chiropodist comes in and does our feet, particularly (wife) and she said, ‘why don’t you have yours done while I’m at it’. So, I said ‘okay’, so I get that, the Chiropodist as well. But the Chiropodist said she didn’t think (wife)was ill enough to warrant going into a Nursing Home and with Care Package, good enough Care Package, coming into the house she’d probably manage okay. So, you know, that’s an unknown.

**Interviewer:**

***How did you find out information about, cos you talked about a bit, about planning in case you need, you yourself need surgery? How did you find out about where you could get help in you would need it?***

Answer:

From our GP (okay). I think from the GP, I, let me try and think, oh gosh. Yes, I think when (wife) was first diagnosed we had quite a lot of input from *(local hospital)*. Ah, the assessed her; and then gave her some exercises to do and things. And we did have some visits to the home from *(local hospital)* physios. Um, and, one of the help things at the beginning of her Parkinson’s, this didn’t happen when we were going privately this only happened when we went NHS. Once we got into the NHS sausage machine, it was really good, um, because we got all these extra bits and assessments and things that we didn’t know you could have. Um, and so, we got given a list of, um, people you could talk to.

Um, I’ve, I’m a member of Carers in Crisis in *(city name)* which I, I think I either got it from the GP cos they’ve got a, a lady who is responsible for Carers there and gives advice and help. Um, or I got it from, from *(town name*), I can’t remember. But one way or another when we went, I mean I went to Carers in Crisis in *(city name)* Council.

I think *(city name)* Council were the people who helped me get in touch with care providers, and then I would have ring them up. I rang round and saw which ones were available and so on. So, *(city name)* Council were very help, it’s amazing. You think that the Council’s a lumbering useless body, but actually when it boils down, if you’re in real trouble quite often if you get hold of the right person they can point you in the right direction. So that’s another avenue that’s helped. So, that’s how I found out about getting hold of help.

Also, when (wife) came out of Hospital once, well twice in 2018, there was a system in place then, I don’t know if they’re existing now, but it was called the BIC’s team, the *(city name)*, something, Care. Anyway, it’s a Post-discharge Team that came in, intensively, for 6 weeks to make sure that you could get back up on your feet and get going again as best you can. And they were helpful. And they were the people who put us in touch with, peop, NRS, with, they recommended various aids around the house and things like that.

Like when you came in the front door, there were rails there. (wife’s) brother came on Monday, this, well what’s today, Wednesday, day before yesterday and he saw the rails and he’s got Vascular Parkinson’s and he was well impressed cos he’s much worse that (wife) and err, so he was well impressed. You could see the cog wheels turning – how could I get this at home? But his home I think, doesn’t have a porch so it doesn’t have anything sticking out. I mean, he could I s’pose build stainless steel rails going down the step that he has to do, if he’s willing, but he’s a very proud man and, whether he’d be willing. I think he finds, much worse than (wife), because (wife’s) a Christian. He finds the loss of capacity far more trying, far more difficult to cope. He’s really struggling. Cos he was very dynamic man, well (wife’s) pretty, I mean she’s a bit of a dynamo as well, but the, the mindset is very different between her and (brother), so there we are.

**Interviewer:**

***And, you know, the medications (wife) showed me. She has a little table that she takes 13 different times a day and um, did you help with that or how did you come up with routine?***

**Answer:**

I put it on a spreadsheet. It was (wife’s) suggestion. And she said I could do with a table, and so I said, ‘well lets, I could probably do it’, and I changed over from Windows where I knew Excel pretty well, to an Apple system. And I had to, first of all, find out how to introduce tables and things into pages which is their version of word. Um, and actually found it was quite easy. Once you know the one system they’re pretty similar. Ah, so I did a spreadsheet in Pages for her.

**Interviewer:**

***And set the alarm she showed me and how you had an alarm.***

**Answer:**

We found, I don’t know how we found out that, cos we’re a bit, we’re not computer nerdy, so we didn’t yet know. Someone told us that you could set multiple alarms on an iPhone or and iPad, so we just went with that. so, it’s quite good, yeah, it’ really helpful. It is incessant because it goes off every couple of hours during the day, but it does help. It doesn’t guarantee that you will take them. Because I will say to (wife) ‘do you want me to turn it off’ and she will say ‘yes’, if she’s out there and the iPad’s over here, yeah I’ll save her the walk. Um, but, between us we manage pretty well; we don’t often miss. But if she does miss there’s a definite drop off of her capabilities. Just 20 minutes you can get away with; half-an-hour is, you know, just about; and an hour is a disaster. Um

**Interviewer:**

**So, you monitor her Parkinson’s and her health?**

**Answer:**

Yeah. I’m on the lookout, all the time. Cos I worked in like a Biology, as well and I would, I don’t tell (wife) this, well she knows I probably do, I dis, I’ve said ‘your urine’s okay’. Cos having done urine’s for years, I know what a UTI urine looks like, pretty well unless it’s borderline. Um, so I check that the urine’s clear in the morning. (wife) self-checks her bowel movements. She makes sure she knows; she always keeps a close eye on that. Cos having been admitted once, she doesn’t want to be admitted again for that. Cos it is it is avoidable. So, I keep an eye, cos that one time, the other time in 2018 that she had Sepsis twice. Once was blocked bowel resulted in Sepsis because the gut floor had got into her blood system. Um, the other time she had a UTI and, we didn’t get the Antibiotics in straight away. Sometimes, ah, I know perfectly well that unless you’ve got a multi-drug resistant drug that It’s unlikely that (wife’s) going to pick one up.

At the moment unless she has a Carer come in, like a professional carer whose, may cross-infect but that’s not happening at the minute so, that’s um, so that’s unless she has an MDR she, her best drug of choice, cos she’s allergic to Trimethoprim, Sulphonamides and, well we’re not sure exactly Sulphone, but anything with Trimethoprim; so Sceptrin, Bactrim and Co-phyproxomole are out. Um, we thought she was allergic to Penicillins because she did have a rash after having had Kethradine and Flucox. She had Flucox first and then Kethradine and I was, the Doc put her on Kethradine I think it was for c, I can’t remember what it was for, a skin infection. Um, and I said to (wife) when we came out the Doctors, ‘I hope you don’t get c-diff’ and blow me down she did (oh dear). But she also came up in a rash, and so they were reluctant to give her Penicillins because of the Kethradine rash. But when she was in with Sepsis, she had Agentupen perfectly normal, no reaction also. We don’t think she is allergic to all Penicillins; she might be, it might be allergic to just Kethradine or maybe something else I don’t know.

Um, so, what was I saying, I’ve lost my thought, I’ve rambled again (you were talking about your wife). I monitor her; I know what drugs she’s allergic to and because she’s had the UTI, which then resulted in Sepsis, she became moribund and then we had to get an Ambulance. Ah, so, yeah, um, I do, yeah. I’m on the, I’m like, you’re too young to know my, this film, this series on television called My Favourite Martian where it was a bloke who looked like a human but was a Martian. And it was very old 60s TV and two little antennae came out of his head when he was not on the lookout of the things, and I’m a bit like that (giggles). So, my antennae are going all the time.

**Interviewer:**

***And, um, how have you found, you know, have you ever needed help or a question or concern about your Parkinson’s what?***

**Answer:**

First port of call is, was, *(PD nurse specialist 1)* at (local area) who I think is still working part-time now isn’t she? *(PD nurse specialist 1)*, she was *(PD nurse specialist 1)* something else before, she’s got married since we’ve known her. Um, and then the other girl who is also training alongside, well she understudied her hasn’t she, she’s, I can’t remember what her name is some French name isn’t it? Can you remember her name? (*(PD nurse specialist 2)*, yeah, she’s good. She’s been helpful. So, either *(PD nurse specialist 1)* or *(PD nurse specialist 2)*, first port of call, question. GP Surgery, they’re pretty good.

I am listed as a Carer, so if anything goes wrong with me, they do tend to respond quite well. Although since Covid it’s been a bit disastrous but, um, in the old days it was, it was okay. Ah, and, so ringing up for advice we have a good system with our GP Surgery. I’ve got nothing but praise for them really. Um, you can, even if you can’t see a Doctor, if you’re ill you can phone up and get a telephone appointment with one Doctor. It won’t necessarily be your Doctor, probably won’t be, but you can get help. So that’s a point of contact. Um, when (wife’s) been, had her falls and things they got a good set of Nurses who change dressings and things quite well, and we know them quite well cos she’s had a few falls and tears of skin and things like that.

so, but, first port of call is either, if it’s a problem with um, ordinary stuff like um, a protocol thing like how do you make the Council sign a Blue Badge request, um, *(Parkinson’s UK support worker)* is the one I go to. She’s brilliant; she’ll come round; she knows that all these applications go, usually go through tick box thing. The computer has an algorithm and says ‘yes’ or ‘no’ when you get something, so she knows what words to use to make it flag up to give you the right answer. And obviously she would do it if you were needing it. She’s very good for, um, sort of protocol issues and, um, *(PD nurse specialist 1)* and err, *(PD nurse specialist 2)* are the other people we would go to.

**Interviewer.**

***And, I suppose, what about out-of-hours, the week-ends and night?***

**Answer:**

Agh. Well,

**Interviewer:**

***Have you ever needed help at that times and?***

**Answer:**

We have. When (wife) got C-Diff she needed, she also got Norovirus once and was continually being sick, and when you got as usual with. When you’ve got a disease it’s bad enough, if you’ve got Parkinson’s and a disease, it exacerbates the Parkinson’s. so, um, so we have had an on-call Doctor come round a couple of times, when she’s been really ill, but that’s been, actually that was. Well we had to jump through the 111 hoop, um, and I had, and I think I had to take (wife) to an out-of-hours GP Surgery on a Saturday once at (city hospital), which was good.

And the, the Pharmacy, the Pharmacy we go to is, is pretty good. I think, you never quite know who’s going to be on duty with Pharmacies cos I reckon a lot of Pharmacists work in a load of whole different Pharmacies and some are really great and some are a bit, not very helpful. They look at you as if you they are exasperated with you. Um, but our Pharmacy, generally speaking, especially if you’re polite to them. If they’re having a bad day, cos I mean honestly, they’re on the go all day every day there. Their Pharmacy, *(pharmacy name)* is literally opposite the Surgery, the GP Surgery so, you know, they get it all, all the time. And if you’re, if you, I’ve found that if you’re polite and kind to them they’re generally if they’re in a bit of a flat they’ll calm down and treat you well. Um, and, but they’ve got that, a good system with delivery.

I did have a problem, there was one issue where, I was getting my prescription cos I was the Carer, I was getting my prescriptions delivered as well as (wife) having hers delivered. And then they wanted to cut down on the deliveries, and so they culled a lot of people, and they culled me. And I actually went round to the these, to the Pharmacy and said ‘look, ah, I understand you’ve culled me off the list. Um, I don’t know if you realise but’, I was, I was free. I was up to my ears in it at the time, probably with both my health and (wife’s) health and at the end of my tether. But I managed to stay polite, but I did say to, I was only just hanging on to being police. And, I said ‘look this is, this is the sort of thing that’s the straw that breaks the camel’s back’.

I said, ‘I’m having a bad enough time being a full-time carer; 24 hours a day; 7 days a week’. I’ve not been on holiday, we haven’t been on holiday for, it, 12 years at least, maybe longer. And I said ‘look I haven’t been on holiday for 10 years; I know I haven’t been on holiday for 10 years cos that’s when (wife) was diagnosed. I haven’t had any respite’. And I said, ‘this is the straw that breaks the camel’s back’. Thankfully the, the Pharmacist who took me off was there, and she’s not particularly easy person. She’s not English, she’s Eastern European person so rather tougher mind set on things. Um, but she, she was good. She, she put me back on. She, they actually said they couldn’t, so I left saying, ‘well I want you to know that I’m really, really not happy’. I said ‘I understand you’re trying to cut down on your expenses. This has probably come from much higher up, but I said if you can do it for me please do, cos this is the sort of thing that would just drive me over the edge. And they did put me on, I got a note or a phone call saying, ‘you’re back on’. So that was good.

So, help wise, you know, they’re good now, they’re great now. Um, but we have had. I think with every, someone with Parkinson’s you always can have an issue with something and if you plead your case as best you can. If it doesn’t happen fair enough but, it sometimes does, does help if you politely plead your case and just spell it out as it really is. Cos they have no idea what you’re going through, nobody who’s not been a Carer for someone with a debilitating disease that needs 24-hour care has any idea what you go through.

**Interviewer:**

***I suppose in terms of all the, all the Healthcare Professionals that have been involved in (wife’s) Parkinson’s, do you feel that your care has been co-ordinated . All the care has been co-ordinated?***

**Answer:**

Um. There was a time when we went over the 6 months before we got recalled for a visit when I did wonder if they were getting inundated with people with Parkinson’s. It’s not their fault but, um, I think to be honest, to be fair, bearing in mind the workload, most of it’s co-ordinated. Yep, I would say, but I would say there could be a bit more physio help with certain things. I think when it comes to Physiotherapy, you know if you get somebody like for my neck. I had to wait months before a got a call to go and see someone. Um, ah, and, I think probably with Parkinson’s, the Parkinson’s Team at Christchurch I reckon is excellent. And they do have, they’re on the same site as the physios so if they have a problem they can go and talk to them there. I don’t know if they do, but they can do.

And so, I think, we’re probably getting pretty good. I reckon its pretty high-quality care, (good) from *(local hospital)*. No, that team at *(local hospital)* is, is good, really good. I would say one of the best in the country, I reckon *(PD specialist)* is one of the best in the Country. I don’t know cos I haven’t been round all the other ones. But I would say his knowledge is very deep about people with Parkinson’s and, when (wife) was laid up with, um, Sepsis, he came round and saw her and checked how she was doing. Cos in Hospital, ah, at that time, which is 3 years ago, getting the drugs on time when you’re an inpatient in Hospital is a disaster cos they’re so hard pressed they forget.

And I mentioned it to *(PD nurse specialist 1),* and she said I have lectures and seminars on Parkinson’s. They said, sometimes only one, or, loads of, 15, 20 people have been invited to come and 2 or 3 have come – just from the workload point of view. So, she says it’s very difficult to get across the urgency of getting your Parkinson’s tablets on time. But the last time she was in, which was the big frightener one, ah when she, I can’t remember what, I can’t honestly remember.

I think it was when she had the blocked bowel. She did get the tablets pretty well in on time, but she was just about to be released, we had everything in place with the BICs team and everything else and um, we had a brilliant Greek Nurse, a Male Nurse called (name) or something like that was his real name but he called himself Bill because he thought that the Greek name was too, too difficult to pronounce for English people and the, um, he didn’t like being called (name) because everyone had heard of Fawlty Towers. Um, so I think he called himself (name). And (nurse), (wife) had a very low grade temperature that morning, and we had everything in place and I said ‘she’s due to come out’ and he said ‘I’m not entirely happy (husband)’ he said, ‘just leave it another hour or so and we’ll see’. Agh, another hour went past and, ah, I think, I think the pills hadn’t arrived for discharge so she wouldn’t have been able to go anyway. And it, the temperature wasn’t going down and he said, ‘I’m not happy to discharge her with a temperature’, cos it was on him to, for the final discharge cos he was looking after her. And, I was talking to him, and with that a Nurse came flying out of the side room, because (wife) had Shingles as well while she was in the Hospital and said her temperature is, what was it, forty something. It had completely spiked, and she was incoherent. And so, you know, loads of people went into the room; fans started going on her and I looked at (nurse) and I said ‘what can I do (nurse)?’ cos I was, you know, I was wrecked and I was really apprehensive.

Err, and he said ‘(husband), there’s nothing you can do’, he said, ‘she’s in the best hands you go home; get something to eat; have a rest and come back this afternoon at teatime’. This was about 11, 11 o’clock. Um, so I went back; called in on our Home Group friends (two names) um, and prayed with them and um, then I went home. And, err, went back teatime. She was sitting up in bed having a cup of tea. She’d spiked, and cos they hadn’t taken the line out they got the Antibiotics in, and so they kept her in another week just to make sure she was okay. So, I don’t know how I got round to that, sorry, I lose thread.

**Interviewer:**

***That’s fine. I mean, you talked about***

**Answer:**

The efficiency of the, the people at *(local hospital)*. Um, I would say, are they joined up was what you asked me. And I would say, they’re pretty good; they’re probably. There’s probably quite, to be, I would think if you were to ask them. Joined up with the wards I think they would say is probably quite a way to go before the wards are educated properly about Parkinson’s patients and medication timing. Um, joined up with physios and things like that, usually if (*PD nurse specialist)* says something will happen it does. Um, but, whether or not in the in-between times, the 6 months in-between times, you know, we probably could, might have benefitted from some kind of advice but, you know when everything, you just work with what you’ve got until the next time. But they are very good at recalling you now. Ah, so I would say, at *(local hospital)* you get, you’d be hard pressed to find a more skilled team in Parkinson’s, no joke.

**Interviewer:**

***Yes. Just a few last questions. You talked a bit about a few***

**Answer:**

I drank too much tea. I’m going to have to leave you again. Sorry (no worries) I’m a bit of a tea boy. So, off the record the beginning of 2011 I had a TURP, so the bladder situation never quite been the same since (giggle)

**Interviewer:**

***I was just about to ask you, you know, your medical condition. So, you talk about arthritis of your neck***

**Answer:**

Yeah, I had a TIA in 2012 in my branch artery. I don’t know whether it was top or bottom artery of the retina. Ah, that, actually I didn’t know what happened cos I wear these bi-focals that are called Executive ones which literally go right across and literally, half my sight in one eye just completely went grey. Nothing, I thought what on earth has happened. Cos I get Migraines, um, and thankfully after about a minute or two it cleared. So I went and saw my GP and he said ‘right it sounds as if you’ve had a TIA but you’re not at all overweight and you aren’t the sort of, you’re not the sort of risk type of category’.

But anyway, he saw me; he sent me to Professor (name) who was the, err, Stroke man over at, err, *(city hospital)*, um, at the time, I think he’s gone past his new now. And he said, ‘no what you’ve described to me is a classic branch artery, retinal artery TIA’. So, I had that, so I’m on Clopridogrelfor that and, err, I’m on Meloxicam for the joint stuff and the back things.

I had a, in 2006 I ruptured a disk lifting a fairly small guitar amplifier, but I twisted at the same time. That’s never been the same since. But, at the moment, that’s not really my problem it’s been pretty well behaved. Um, so I’ve got the, the big problem is the neck. The thing which started in about 2 years ago when I was washing up, I thought I’m having real trouble pulling my head back; it just doesn’t feel right. And I, I was really struggling. For the first time I literally had to physically pull back and hold my head back. Um, I thought this is not right. So anyway, that’s under control, under investigation. Err, I don’t think they’ll be able to do much for me.

I have, when I had an Epidural for for this lower lumbar disk that went, um, my heart rate went up to 120 for a fortnight and, err, when I take. I get allergic Asthma, well it’s probably, well it is allergic Asthma, but it’s got slightly worse over the years, but I suppose that’s the way it goes. Um, err, it’s pretty well controlled, um, but recently I’ve had to take more Ventolin. Err, I have an emergency, um, Amoxil 500 that if a get a, if I ever get a cold I always get a chest infection and I always need to get, take the Antibiotics.

Err, other than that, I’m, it’s pretty debilitating now with the neck cos, what caused me to really flag up. It was looked up a year ago, with that MRI Scan, um, and I was given some physio exercises, the Physiotherapist. The first time I’ve ever been to a Healthcare Professional who looked at my notes and said, ‘I don’t know why they’ve sent you to me’. And I said, ‘what do you mean?’ He said, ‘well, ah, I’ve just seen your scan and I don’t know what I can do about that’. and I said ‘I’m not expecting you to work miracles’. I just, I had pins and needles in my hand and down my arm, both hands and both arms. And I said, ‘I don’t expect you to work miracles I just need you to give me some exercises, show me some exercises that I can minimise, if possible minimise, the problem’. and at that he sighed a bit of relief and then gave me some exercises. It was good after that. Um, so, um, now having done those religiously um, I don’t have any pins and needles. Well that’s about it really, I’m sure there are other things I can think off but nothing today.

**Interviewer:**

***What do you do to look after your own health?***

**Answer:**

Well, I, I was doing Well Fit exercises that the GP sent me on when I had my TIA, um, and my back. I think it was my back really. Um, so that was initially gym exercises in the Physio Department at *(city hospital)*. And then when that, I think it was 12 weeks or something, and then um, they referred me to (local hospital) under the GP Referral Scheme. So, I, I got, then I got, I had tried before the GP Referral thing and done tailormade exercises made for me, for my, for my disk problem.

But then another time, they sent me to the Well Fit Class which was much better. it was full of people, 60 or over, who have all either had, recovering from Cancer operations or other operations, or, um, and lots of people with back problems. Um, and I, I, used to go once or twice a week for those for an hour.

Um, since the lockdown that all shut, err, shut, but I have been endeavouring to, at least once a week, do the exercise regime here in the house.

But what flagged up the neck problem had got worse was I decided I felt a bit banged up here and said to (wife) ‘I need to get out’, so I went for a mile and a half walk; stiff walk and err, and after I’d gone half a mile I was finding I was problem turning my neck left to right. After a mile I had about 5 to 10 degrees either side, and when I got to the top of the road I was down here, and I couldn’t do that, so I thought something’s wrong. And I had an open-ended appointment at *(local hospital)*so I could phone them up and flag it up that it had got worse, so that kicked off what’s going on now so.

**Interviewer:**

***And I suppose just, does your own health affect your ability to look after, help look after your wife?***

**Answer:**

Oh yes, its classic. It can do, I mean I’m, I’ve got this Umbilical Hernia which has happened in the last 6 months. Err, that’s mild and I’m careful. We’re fortunate that we live in cul-de-sac where, at this end of the road we practically all know everybody which is unusual in England. People are pretty isolationist, but here (wife) gets her hair done just at the house literally over there so it’s 25-foot, 25-yard walk to get to (hairdresser).

We have a builder, a person who used to fit kitchens who did our kitchen, he doesn’t do that anymore, but we know him and his family. I taught his son guitar. Um, so, (two names) we know from Line Dancing when (wife) did Line Dancing. Agh, so, we, we all know each other so if you get into a fix like when (wife) fell in the garden and I had to go and get help to try and get her up, from (name) so, that’s, that’s where, and our Church Home Group is very good as well.

You, we, cos the Church is, membership is about 400 so it needs breakdown groups to have a meaningful friendship with people. Um, they divide it up into like, postcode areas almost. People fall in roughly the same postcode get put into the same Home Group up to about, I think the maximum we would have is 16. We’ve got a regular amount of about 14 now, but we’ve been doing that on Zoom at the moment. But come the 19th we might be able to meet up again.

So, there’s always someone I can phone for help but, the people who live in this area are, generally speaking, you know the youngest is 62, something like that and then the oldest is ninety odd. So, you know, there’s limits on how much help they can give. But there’s always someone you, I can phone cos, cos the Church is a community I have other friends that are not in the Home Group because (wife) and I, we got married at the Church we met, actually we met from being in the same block of bedsits that the Landlord only had people from (church) and people from the local Orchestras when I went. Because, everybody else he had trouble with, defaulting on their payments. But people from the Church and people from the Orchestra he could rely on to pay their, their rent.

So, as a bunch of us lived in different bedsits. He had this huge house that he divided into quite a decent flat for him and his wife. They lived on the premises. And then nice bedsits for everyone else. Ah, I had the worst one cos I was up in the apex of the building, in the, in this small room but it was good enough for me.

And err, that’s where I met (wife) through, we were very involved in youth work in the first 10 years of our marriage, so we know lots of people that are a bit younger than us who are, who work with in with the youth who are still at the church. And we even know youngsters who were in our …. Group, who are now married with children (giggle). So, time go by and we’ve got quite a network of people that we know. So, if push comes to shove, there’s always someone you can phone. So we’re very fortunate in that, the good thing with being in Church is that you’re in a Community and you’re not, I mean some people who get Parkinson’s literally they, they only know family and they might be miles away. They don’t know any of their neighbours and it’s a very different kettle of fish for them. And of course, being here, as well, in this cul-de-sac, cos it’s a cul-de-sac you get to know your neighbours, so there you are.

**Interviewer:**

***But have you got anything else to add, otherwise I haven’t got any more questions?***

**Answer:**

No, it would have been really nice to have been warned about the Peristalsis thing. Um, but I don’t know. There again, does it happen to everyone who has Parkinson’s I don’t know. Um, so can they warn you about that, I suppose they could warn you and say it might happen. But there again, if they load too much of it might happen they might break you when you’re first diagnosed, you know. *(PD specialist)* is very clever in the way that he doesn’t open the floodgates of the poison that is Parkinson’s’, you know. He’s quite wise in, in the way he introduces you further and further down this horrible line that you go down. Um, and I’m quite certain there are some things that we still don’t know that might happen but might not.

I mean, if I’s assumed, like our friend (name), um, who is the father of actually one of our kids in our Church Group, um, who died 10 years afterwards. If I’d assumed that happened to everyone, we’d have assumed that this would happen to (wife). We have quite a good, I would say we’re never bored; we’re never at a loss for things to do even though we’re banged up at home most of the time.

We’ve got so many interests; I’ve got so many interests that I haven’t got time to do all of them properly. Um, and, (wife’s) not short of interest either um, so I think, I think, well one could always. I think one thing which has probably has, I’m somewhat, as a Christian I look at the money being spent in the NHS and some of the money being spent in the NHS is well and truly spent and jolly good.

And other stuff, either because I don’t understand the situation, um, for example 10 years ago I didn’t really understand people with ME. And I thought it was just a figment of their imagination, a bit, it always seemed to me that the type of people that we knew who had ME fell into a particular personality type. Um, but actually, now, I’m, I know something’s going on cos I know more people with ME who don’t fit into that personality type who are really debilitated by it.

So, some of the stuff I think is a waste of money, I, such things as I guess sex changes; changes in things; people can go to your Doctor and say ‘ah, it’s bad for my mental health to have breasts the size they are’. And, you know they’ll get referred, they might get the breast work work done so they feel better about themselves. And I suppose, it’s very difficult to judge. The Lord says, ‘don’t judge’, and so, I’m not going to judge, but it does seem to me that some areas of the NHS, it’s more critical to spend money on than others and we. There is limited funding and I think some areas are probably getting money that would have been better spent on others, but I guess, even then, I’m clouded by the area I’m jammed in. I’m clouded by my gender; I’m clouded by, ah, the fact that I don’t, I can’t put myself into the mind set of somebody who’s suffering with questioning who they are etc. I mean some of those things are definitely the church has got something to say about and can help. And, err, other, other things I’m a bit perplexed about. Why money is spent in certain areas.

But other than that, no, I can, I can, I, also as a Christian, both of us know there is a limited amount of money that’s available in the pot. And, having known our friends (2 names) who have, (man) retired from being a Manager in a Bank quite early. He took early retirement, um, after he, he was the poor guy. Because he was really good, empathetic with people, they put him on the Redundancy Programme to break the news that someone was gong to have to made redundant. And at the end of it all, that came to an end, his job, doing that came to an end. So, I think they said you could go this way, or you could take Voluntary Retirement yourself. He took Voluntary Retirement, and he’s always wanted to, felt a real burn for the poor in Africa and he and his wife twice a year have been out working alongside an African, Malawian Pastor in the poorest area of Malawi; dirt poor. And honestly they, you know, they came across a guy who was sleeping in a leaky grass hut with, you wouldn’t give a dog the blanket he was on, and they, obviously they managed to give him some help there.

And but, um, we’ve got an NHS here; a system that is extraordinary; it’s a gem; and its beautiful. And I think people forget how wonderful it is having an NHS. So, I’ve really got nothing but praise for the NHS, and particularly the team down at, down at Christchurch, you know. And in a crisis, had a few friends who’ve had big serious health issues, the NHS comes up real trumps.

**Interviewer:**

***It’s a great note to end (giggle)***

**Answer:**

Leave it at that.