# Focus Group 1

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| PD specialist 1  PD specialist 2  P01 – diagnosed PD 15 years  C01 – daughter caregiver, PD 7 years, non-cohabiting |

**Moderator:**  
So firstly I would just like everyone to introduce themself. If you could please just tell us how you would like to be called today and what your role is in the care of Parkinson's. And I'll start by at the order of my screen. So, (name)

**PD specialist 1:**   
Hello, my name is (name). I am one of the elderly care consultants working out of (hospital) with a specialist interest in Parkinson's disease. So I do a clinic on a Monday afternoon twice a week, so I'm commissioned. I'm paid to do two clinics per month at the (local hospital).

**Moderator:**  
Thanks, (name). (Name)  
  
**C01:**  
My name is (name) and my father has Parkinson's. So he is 86. He was diagnosed about seven years ago. I don't live with my parents. They live about 10 miles away from me. But I take responsibility for all of the medication, hospital, GP appointments. And I'm also looking after all of their finances and bills and all that kind of things as well. So that's kind of where I would fit into this.

**Moderator:**  
Thanks, (name). (Name)   
  
**P01:**  
Hi, I'm (name). I've got Parkinson's. I was diagnosed about 14 or 15 years ago. I live with my wife who is increasingly having to take care of me. It's probably only been in the last six months that she's had to sort of be active in things like helping me get dressed occasionally. And things like that. I still look after my own money. It's not that I don't trust my wife. It's just the habit we got into over 40 odd years. That's about it I think. I'm still fairly active in running music recitals and lecturing, but it's becoming harder.

**Moderator:**  
Thanks, (name). (Name)

**PD specialist 2:**  
Yeah. Hi, I'm (name). I'm a geriatrician at (hospital), as well as doing Parkinson's disease is one of my specialty interests. And I also have been a relative of someone with Parkinson's disease. So my mother-in-law had Parkinson's for 19 years and sadly died at the end of last year. So, yeah, that's I've seen both sides of the coin, I think.

**Moderator:**  
So before we start our discussion, what I'll do is just briefly summarize the main issues of treatment burden and capacity in Parkinson's and the main issues that we found from our previous work was issues related to attending appointments, access to healthcare professionals, getting information about Parkinson's and also things about managing your prescriptions and medications. And what I'll do throughout this, you know, over the next hour or so, is discuss ways to improve each issue in turn.

So starting with the first one. At the moment the current national guidelines for Parkinson's recommends, you know, 6 to 12 monthly follow up appointments. But some people have Parkinson's, you know, report dissatisfaction with how frequently they're followed up, with some people wanting more appointments but actually some people finding that there's too many appointments or too many follow up appointments. And I'm not sure what you think, how we can help with this or what your thoughts are to improve this dissatisfaction with the frequency of appointments.

**PD specialist 2:**  
Well, I'll, I'll start off. So I I think, (Moderator) that. I think so. So the (local) service where I've been working has been really struggling with appointments for patients and I think we've been giving them a pretty rubbish service to be truthful. And I think there's a real there's a real mismatch between what the Commissioners of the Parkinson's service want and what the patients of the people with Parkinson's want. And actually, what the clinicians who are looking after with them what. So I would really like to be able to see a person with Parkinson's whenever they would they feel they would like to be seen.

But at the moment, certainly the last five years in (local area), the view of the Commissioners has been, well, NICE guidelines are once a year, you know, 6 to 12 months. You shouldn't be seeing them more than every 12 months, once every 12 months. And that has been so difficult to manage and so unfair on people. And at the same time, the Commissioners in our area have reduced our Parkinson service. So I used to do 3 Parkinson's clinics a week and now we have one and funnily enough, three clinics a week into one doesn't work. And you've got a lot of people. I'm dissatisfied. I'm seeing people that I could be helping if I saw them a bit earlier whose illness is being allowed to progress because they can't access the care and support they need.

**Moderator:**  
(PD specialist 1)

**PD specialist 1:**  
So I couldn't have put that better myself, to be honest with you. And it's reassuring, but also very dissatisfying that that's exactly the same issue that (local area) have to what we have at (hospital) and in the surrounding, sort of (local) areas. And it is a commissioning issue and. And no matter how many times we kind of bang on doors, it is a challenge to improve that and will always take time.

And obviously patients need to contact us and we're not on a patient…, the other thing that you can do is go towards a patient initiated follow up and so patients can say…and and you can have a minimum break on that. So, you can say to not let the service become overwhelmed, say that it would be minimum four months, six months, whatever. But then if patients that you refer to don't want to have a frequent follow up, they can say I don't want that appointment in nine months. I'd rather it be a year. I suspect it would be the other way round. They'd want to be seen more quickly and it's just a capacity issue for us in (local area) and unfortunately for me there's a spillover in so much that people will then phone my secretary. I don't know if you get this (PD specialist 2) asking for help, which is entirely reasonable or their GP's will, and within my three day a week practice, there is no other capacity. I have no time apart from outside of work to phone patients back and I and I'd love to be able to because clearly they need that help. But there's, you know, and it's, I find it really frustrating. And that's the not solution. That's just a description of the problem. I know that's not what you were after.

**PD specialist 2:**  
Yeah. And I think the other thing if I may jump in it again is that I think it's also really stressful. So I actually went off work with work related stress last year and that was predominantly relating to the Parkinson service and the fact that I was meant to be there for half or you know one clinical week which turned into a whole day's clinic a week but which then turned into me just being constantly every other day of the week when I'm trying to do my other roles over at the acute hospital being troubled with queries.

And I think you know, I think we've in (local area), we've lost we Parkinson's nurses in the last couple of years and they've left because of stress and workloads. And I think that's really sad and I know from my mother-in-law she really struggled to get hold of the Parkinson’s nurse. And actually I struggled to get hold of the Parkinson's nurse even, even though in theory, you know, I could use my NHS net account and be a bit sneaky with it. Parkinson's nurse never ever replied to me when I contacted her so.

**Moderator:**  
Yeah, that's a (name) said. (C01)

**C01:**  
I completely understand this this dilemma over how much people want to be seen. I think from my father's point of view, early on in his diagnosis, every 12 months was absolutely fine. And things were just pottering along. He wasn't too distressed, but when things started to change and started to shift, it was then extremely frustrating to not have anyone I can contact on his behalf to say “I've noticed this change and I think this is Parkinson's. I don't really know and I don't know what to do about it”.

So, I don't know what the solution would be to that, but there's definitely something about access and about an ability to say, “well, actually this year it's fine. This year I don't need to be seen more often. I'm going along.” And actually they're not much fun, outpatient appointments, in the nicest possible way. So let's not do that , versus “Actually, there's been a shift. There's been a change. Somebody's worried. And now I would really appreciate an appointment, even if it's in six weeks time.” I would appreciate that ability.

And I can hear you talking about the Parkinson's nurses. We've actually just lost access to our Parkinson's nurse completely. My father's just had a letter saying they've taken away the appointment he had and there's no more appointments, so without any explanation. That's frustrating. I mean, we're fine because I can keep an eye on things and I know what I'm looking out for, but I would be concerned about people who didn't have that level of knowledge or even an ability to find answers about what they would do without access to someone. Even if it's not an outpatient clinic, even if it is a nurse.

**Moderator:**  
Yeah, absolutely. I think, (P01), I'm sure you have some thoughts too.

**P01:**  
Yes, until recently I've had no problems. Generally, over the 14 years I've had an appointment about every six or seven months the only difficulties I've ever had are with Parkinson's nurses. Whenever you ring them? I'd occasionally get a call back. The record was six months later after I'd left the message. I understand the problems that they've got.

The difficulties I'm beginning to find now or as (PD specialist) once said, for goodness sake, you're getting old, you can't blame everything on Parkinson's. You don't actually know whether what's the latest symptom is actually Parkinson's related or totally unrelated? I promise I won't give you all my current medical history, but in the past three months I've been to the optician to get new glasses. And when I've asked her about the problems I've got with my vision, she says “Ohh, that's probably Parkinson's.” How do you follow it through?

And then this week, because I've got a problem with my arm, I went to a physio. Who has giving me some exercises to do and I'll see him next week. I went privately. Because what do I do? Do I go to the surgery? Because it may be Parkinson's related, but then again it might not. If I go to the surgery, I'll still be sitting here in agony in about 3 months time. So it's the.. I'm not sure how well it's. It's the joined up approach to Parkinson's, which I think is really difficult because Parkinson's itself is so fragmented in terms of symptoms.

**Moderator:**  
Yes, (PD specialist 2)

**PD specialist 2:**  
(P01), I would complete the echo that. I always feel that people with Parkinson's get a really rough deal because as soon as they're diagnosed with Parkinson's, any symptom, they go to anybody with is laballed as “It’s you Parkinson’s. When do you next see the Parkinson's doctor.?”. And over the years I've had people who've been declined knee replacements for osteoarthritis. I've had GP's who won't give painkillers to people with osteoarthritis. I've had a lady who actually developed spinal stenosis and needed an operation who actually went to her GP, saying “I have got quadricep weakness.” She was a retired physio and leg weakness on one side who was told it was her Parkinson's. I've had letters from urologists saying “I've just done this TURP on a patient and I reviewed him in clinic. He's doing really well, which is fantastic. However, I see he's just been diagnosed with Parkinson's. If I'd known that was about to happen, I wouldn't have operated on him.” And I think there's a real discrimination and a real lack of support for people with Parkinson's.

**P01:**  
If I can come back very quickly. There I had a TURP about 10 years ago And the surgeon at (hospital) worked very closely with the neurologist. Whether that was just because they happened to hit it off or not, but I've that was one occasion I really felt it was being treated as an individual. Both of them explained the problems. I was known as that bloody man who's got Parkinson's and prostate problems by the surgeon. But it did work out.

**Moderator:**  
Thanks, (P01). (C01)

**C01:**  
Yeah. See, I think it one of the things you put on the sheet that you sent out was about communication and about information about Parkinson's. And I thought I was quite well informed until my dad was diagnosed and I discovered, I know virtually nothing about Parkinson's. I don't know the symptoms that you're looking for as Parkinsonian symptoms versus what we think might be Parkinson's symptoms. And when my dad has, as I said, he's 86. There are other issues going on.

I don't know which is which and which are going to be helped by a Parkinson's appointment and which actually needs a physio or something else entirely. We're fortunate we have GP who's keeping on the ball with it, but if she wasn't, and she definitely doesn't just assume that everything has Parkinson's with my dad, which is great. I wouldn't know how to tell the difference. I had no idea how individual the symptoms can be. How their presentation is completely different. So my father was given a lot of information when he was diagnosed and I've kind of put it at the back of the cupboard, because it's not his story of his Parkinson's, and I neither want to alarm him about possibilities nor give him any ideas about things that might happen. But it then means you're left going, “Well, is that knee problem Parkinson's, or is it just something completely different? It should we actually be an A&E right now, not anywhere else?”.

**Moderator:**  
Yeah. Yeah. And I think that's all very important points that we've brought up, you know firstly obviously to do with the commissioning and appointments and frequency appointments and access. And thinking of ways to improve that. I know (PD specialist 1) mentioned slightly about patient initiated follow up which I think has been used in other specialties. I don't know of any local services around that have used it for Parkinson's and that could be an option. But if anyone had any thoughts about that or any suggestions of how to improve that.

**Moderator:**  
(PD specialist 1)

**PD specialist 1:**  
So I think I think they were trialing it in (local region)

**PD specialist 1:**  
But the difference in (local region) and I think it's just sort of been luck and maybe how the service has been commissioned and set up is that the the consultants and specialists don't have anymore appointments I think than we particularly have as in (PD specialist 2) and I but they're Parkinson's disease nurse is full time and there's maybe two or three of them working out of (local region).

And which which I think is the way around it should be. In so much that you get a, you know, an experienced PDNS or several of them, who are accessible and they can be phoned with these queries, “Oh my dad's got painful knee is that PD or not?”, and they've got access to firefight and then if they need an appointment with either the nurse or the consultant brought forward then there's capacity to do so.

As you say, (local area) has lost the PDNS recently, which leaves officially, commissioned two afternoons a month for all the PD in (local area), which is ridiculous. Because even if we were on a patient initiated follow-up pathway, I don't have the appointment slots to give for them, which is awful. But as I say, (local region) is doing it and I think it is working because they're correctly set up.

**Moderator:**  
Yeah, (C01)

**C01:**

So I'm aware that this isn't about Parkinson's. My mother has rheumatoid arthritis. And their system which I have found to be easier to access is exactly as you've described (PD specialist 1). It was nurses and a phone number for the nurses. And had a query and there was something my mum was bothered about. I didn't know which way to take it. Ringing the nurses, they both answered the phone and there and then and had sorted the query. It was pretty much the end of that week and had told us, you know, that bit wasn't urgent, but they could try and arrange something else.

And certainly from a patient point of view, it didn't matter that the appointments weren't immediate. It just helped that there was someone who could give us some advice and also she then decided that actually my mother does need a consultant appointment and has gone ahead and arranged that. So that idea of just qualified nurses who can give both advice and take it forward. It's the moving it on to the next step if you need it. It certainly has worked very well in that service. I haven't had the same access in the Parkinson service at all. Yeah, that's the nurses just haven't been that available.

**Moderator:**  
Yeah, obviously there was some suggestions about, you know, who, who do they go to as a problem and you know, PD nurse specialists, PD consultant or their secretaries. And you know the aim is or the drive is really towards general practice as well. You know GPs are meant to be there to be their first port of call, and I'm sure from your experiences and from what we found in our study that actually, difficulties accessing GP was another contending factor that didn't help with access to any healthcare professionals what more whether it’s Parkinson's related or not. And the lack of coordination as we spoke briefly about you know between GPs and PD nurse specialists between hospitals and GPs and other specialties in the Parkinson's specialists and the lack of coordination. And I don't know what your thoughts are about how we can improve you know the care coordination for people with Parkinson's and we mentioned some of the challenges earlier and the labelling, fragmented care and what your thoughts to improve this?

**PD specialist 2:**  
So one of the things that we used to have in (local hospital), we still have at (another local area) for the Parkinson service is that actually there are a couple of the nurses who are in the day hospital environment who themselves, although they're not Parkinson's nurse specialists are sufficiently upskilled that they can deal with the querie and signpost people appropriately. So that still goes on in, in the (local region) bit. But in (town name) as those nurses retired, the new nurses didn't take on that role. So you know previously the nurse would say well, find out what was going on, would know the common problems, would be able to ask the questions that might indicate that they needed to see somebody urgently, and it wasn't their Parkinson's. And I think that that used to make a real a real difference for people.

**Moderator:**  
Yeah, yes. So the upskilling of you know other people around in the service here not not just you know a sole person per say yeah, that's interesting thought. Yeah, very helpful.

**PD specialist 2:**  
Yeah.

**P01:**  
I've, something just come to mind. It goes right back to the 14 years when I was first diagnosed. I had a GP who didn't believe in giving medication for Parkinson's in the early stages. And fortunately, because of the job I was in, I was able to pull a few strings and get to (London hospital) and see one of the consultants there who immediately overturned that decision by the GP. I don't know how aware GP's are these days of Parkinson's, whether they're better than they were 14 years ago.

**Moderator:**  
It's upskilling of knowledge. Yeah, (PD specialist 2)

**PD specialist 2:**  
So I was just going to say that I think, I think it depends. So I think because I've been doing Parkinson's disease clinic since 2006 and spent every single year going out and train GP trainees on Parkinson's disease and train hospital doctors on Parkinson's disease, I think they've all got a lot better, certainly in my part of the world. So that that's one of the issues we have with capacity is the referrals have gone up because people are recognizing it and they're recognizing perhaps some of the non-motor symptoms a lot earlier.

I mean GPs are very much encouraged via NICE guidance not to initiate people on medication without them seeing a specialist first, which I think is still the correct thing given that we know that they're not as, they don't have the same level of expertise and experience in initiating drugs.

**P01:**  
I’ve actually got very good relationship with my present GP, who seemed to work very closely with (PD specialist) predecessor. Whenever I.

**PD specialist 2:**  
I think that's the thing, isn't it? I think if GP's can literally pick up the phone or ping us an email that makes all the difference. And again, you know there are some GP's that I work with who they've got my mobile number, they know they can phone me if they've got a problem with someone with Parkinson's, they know they can ping me an email. And I think there is something about us all being a little bit more joined up rather than having to be at, you know, they dictate a letter via that which then the secretary types, which then get’s put in the post you know, I mean it's all snail mail still.

But for a lot of the communication, and if we had, you know, if we had this whole system where we could all actually communicate a bit more easily, I think that would make a huge difference. I mean, I am very interested to see how the new PD Connect service that Parkinson's UK have launched is going to work because I that sounds like that could be really, really good if it does what it says it's meant to do.

**Moderator:**  
Yep. Yeah, I think I absolutely. The speed of communication between services at the moment and probably needs to be improved as (PD specialist 2) said. Unfortunately, the dictating letter is a very much traditional way of doing things at the moment and for communication. and I'm sure patients and caregivers fine problems with that, you know with various ways trying to negotiate things in between the meantime.

And the other thing about appointments is obviously been the change to telephone appointments for some people due to COVID obviously as a push due to the pandemic. But obviously some services are still continuing a mixture of face to face and telephone appointments. People with Parkinson's and caregivers from our study didn't really like it because they found actually the speech they can't hear you, they can't be heard over the phone, they can't describe the symptoms and actually felt that Parkinson's is something that someone needs to see how I'm doing. I don't know in how we can improve this. Obviously, telephone appointment can help in some ways with capacity for healthcare professionals on one end but not necessarily might be the right thing for the service users. (PD specialist 1)

**PD specialist 1:**  
And so I obviously took over the PD service from (PD specialist) during the pandemic. And I would say that for the previous probably about a year, all her appointments had been telephone because they had to be. And there was two kind of, I would say, distinct groups of patients in this scenario where by some didn't want to come back in to the hospital because it was difficult with mobility and they were more disabled and things have changed, and clearly that was a bunch I needed to see.

Because actually for the most part, I felt with lots of them they hadn't wanted to tell (PD specialist) that there'd been a deterioration because they were so terrified that they would get COVID be yoinked into a hospital environment to be seen, that when I insisted that they came, lots of them came in really undertreated and quite unwell. And this was you know, a group of 80-90 patients that I had never met any of them. And they were all turning up to standard clinic appointments really unwell. So when I first took over the clinic, it was a bit like ohh my word, it was a bit stressful.

There's also, this is a smaller group of patients in the (local area) Group because it just it but they they probably don't need to be seen face to face at the moment and coming up to hospital is a hassle. But, having just taken over all these patients, it's difficult to work out who is who in that scenario without sort of saying, are you not coming up because you're really unwell or are you not coming up because you don't need to. So it would be nice to go to some telephone. I would say they do not save me time. I end up speaking to them. I then have to probably speak to a carer who lives not there. They are not, in my experience, they have not saved me time. They save the patient's time and I get that in terms of burden, but I don't, it's not efficient. That doesn't mean to say that maybe video conferences where you get the nuance from the carer of how's their driving and their, (shaking their head) you know in the background which you don't get over the telephone. Umm, so I think in future would be nice to go to, to a hybrid but at the moment coming out the pandemic, I think it's been helpful to see everyone face to face.

**Moderator:**  
I think C01 has something to say as well.

**C01:**  
So yeah, I mean I would echo that. There's been something about the two years over the pandemic and that yeah, people need to be seen. And it's particularly my parents generation, they just don't say when things aren't quite as good, they’re just not telling it. We've had a different issue with the telephone appointments and my father's really profoundly deaf. So telephone appointments were an utter disaster. And I actually just ended up refusing them and said I will come wherever you want me to come and I will wear whatever masks you want me to wear. But I we can't. There's no point in us doing this over the phone. It's just so most. In fact, I think all the clinicians I’ve spoken to were happy to accommodate that in the end and said, yeah, that's has to be done. But there's no doubt you pick up things when you see my father that I wouldn't know to tell you. That's definitely true.

**PD specialist 1:**  
Yeah.

**Moderator:**  
(PD specialist 2)

**PD specialist 2:**  
I think so. We tried. We tried a bit of both during the pandemic and the problem we had with video calls was the fact that quite often that we had a phone that worked and that could do it. But the people the other end either did or didn't have a phone and often reception. So there was a lot of issues with actually the quality of it. And I know one of my colleagues spent hours calling people, then recalling people because they just couldn't get the technology to work. So I think, I think that's the that's one of the issues with the whole video calls is the technology and the matter of time you can spend sorting that out is a bit of an issue, I think.

Some some people you could. Some people do prefer a telephone appointment and maybe that's something we should be, I think particularly in the earlier stages. I mean one of the things we do because we have such capacity issues is the nurses in the clinics actually phone people a couple of days before their appointment to say, “Are you aware you've got an appointment coming up?” because we really, you know if you havesomeone who doesn't attend, you know that realistically the next slot you're going to have for them will be like 9-12 months away.

And and as part of that, that has also generated sometimes when they phone, people have said, “Do you know what, I don't need to come in and see this person see the doctor at the moment, I'm actually fine. Could we leave it for another six months and I'll get back to you?” So I think some people will take advantage of that. But again I think it's something about asking people.

**Moderator:**  
Yeah. So, perhaps asking people, you know, at the end of the appointment, you know, how would you want your next appointment, you know, telephone, how often do you want to be seen or and and then, but also giving them that flexibility of. But if things go wrong, there is someone that we can call in the meantime. But it’s having that system in place to help that. That's great.

So we've talked about, you know, kind of appointments and access to healthcare professionals and and moving on really to the next issue of otreatment burden which talks about information and I know (C01) mentioned it briefly earlier about how much there is that actually you don't know or and having that knowledge of how much you don't know is also useful but also, as you talked about actually people with Parkinson's and their caregivers, some people don't actually want to know what can happen with Parkinson. There’s a lot of information out there, which as you say, are not actually relevant to their situation at that time in point. And everything is so individualized. So getting the right levels of information, at the right time for their situation was challenging and added to their treatment burden. And what do you think about the ways that we can try and improve this aspect really?

**PD specialist 1:**  
I can talk a bit about that if that's helpful. And so I really like the PD UK leaflets that they have and since I've taken over the clinic, I now I've ordered loads of them, so I've got a big folder that's colour coded but with all of the relevant leaflets in. And the thing I like about it, is that they're all specific to different conditions. So you can say, right? You know that this patient has started talking about their anxiety and there is a leaflet pertaining to that. My general age group of patients, most of them don't have access to the Internet. So these are all available as PDFs online, but most of them prefer a paper copy, which is why I find it quite useful.

The other reason I find it useful is that it helps them to appreciate you know, someone. This is a common problem in Parkinson's disease. It normalizes whatever it is, constipation, skin disorder, whatever. It's so common, in fact, that there are leaflets about it. So you're not alone, is what I'm saying in this. And if they don't want it, they can say “I don't. I don't want it.” So it's something that you can, you know, really individualize to them. So that's why I quite like having them all. That said, and apart from the, you know, the kind of summary and the title, have I had time to read all of these leaflets I'm giving to people? No, I haven't. So if they come back to me and said, oh, it's suggested whatever in there. So I'll be like, oh, God did it. Sorry.

But you know, I'm not infallible and but I really like the. And also it stops them from going off onto Wikipedia or doctor Google and finding, you know, blogs of people that have some ghastly things happen to them, which is not helpful, I think.

**Moderator:**  
Yes (C01)

**C01:**  
Yes, yes please can. Can I get access to some of these leaflets? That would be extremely helpful. We've, when my father was diagnosed, which I think was seven or eight years ago now, it was just a pack of too much information. That quite a lot of it didn’t really relate to the symptoms that he has. And my parents very definitely have very narrow views of what Parkinson's does and doesn't consist of. And they had a very set to view of how it was going to go, and what was gonna happen to my dad. Which actually hasn't happened at all. We’re dealing with a whole bunch of other things, not with what they expected. So to have something so individual and about individual symptoms, yes, it would be extremely helpful. And this whole normalizing it. Trying to persuade my parents that some of the things my father is struggling with is A: due to the Parkinson's, and B: completely normal for somebody with Parkinson's is extremely helpful because it's so difficult to get them to accommodate. Yeah. Really anything other than a tremor that they're kind of stuck? With anything other than the tremo. So, so please. Yes. Can I have access to the leaflets? It will be extremely helpful.

**PD specialist 1:**  
Yeah, yeah, they’re all online, but yeah.

**C01:**  
I’ll read them, (PD specialist 1). I'll let you know if there's anything dire in the background, Somewhere in the small print at the very end of it.

**PD specialist 1:**  
Actually. Yeah

**Moderator:**  
(PD specialist 2), yes.

**PD specialist 2:**  
I think it's about getting the right balance of information, isn't it? And I think the tendency to have always given out like a pack has, you know, a lot of people have said what you said, (C01). It's been put at the back of the drawer. And actually I say that to people when I give them their information pack, I’ll say, “You may not want to read this right now. It's there for if you need it in the future.”

But I think it also helps people be a bit more proactive. So my mother-in-law, when she was diagnosed, she clearly read all the leaflets cause one of the first things she came to tell me as a daughter in law was, “do you realize I might get dementia?”

And you know she clearly took that on board, but I could completely get that for other people that would be really distressing to hear that, as you know, like the first thing first bit of information you've got from your Parkinson's consultant. But I think it also for her, cause again it depends doesn't it there are some people who are ostriches who will stick their head in the sand and not want to know anything and there are other people who want to know everything.

But I think it helped in terms of trying to support her as her illness progressed because things like power of attorney, I had, it was easier to talk to her about. It was easier to talk to her about some of the advanced care planning that perhaps you know we needed to put in place to, to ensure that she was treated with dignity and thatthe right thing was done with for her. There's one particular Parkinson's. Well, there are two particular Parkinson's leaflets. I absolutely loathed. And I don't know, (PD specialist 10 if you've even tried to give them out to the people. One of them is End of Life in Parkinson’s. It's honestly, I mean just just putting end of life on the front. Nobody's gonna want to read that

**PD specialist 1:**  
OK. Oh, I I didn't order that one.

**PD specialist 2:  
A**nd the complex one are just they are just you know I never give those out because they they they always land really, really badly. Considering the rest of their leaflets are so fantastic and good, And I have read most of them (PD specialist 1) at one time or another

**PD specialist 1:**  
Yeah. I will do sorry.

**PD specialist 2:**  
Well, no, it's alright because because that's the beauty that, you know, I think people working with people with Parkinson's, it's very much about this partnership approach, isn't it? It's about helping put people in control of their own illness and making them the experts. And you know, actually I think it's great if someone comes to clinic and says, “Do you know what, (name), I've just read such and such, you know, in the Daily Mail or it was in the Parkinson's leaflet, you know the newsletter.  
What do you think about that? What are you aware of it?” I think it's absolutely fabulous. So, I think the, I think the leaflets are good, but some of them need a bit of work.

**Moderator:**  
(P01)?

**P01:**  
I would be very careful what I say now. It was for three.

**PD specialist 2:**  
No, say whatever you like.

**Moderator:**  
Yeah, please take.

**P01:**  
No. Well, for three years I was on the Parkinson's UK editorial board. I had grave concerns about their ability to present some material. I'm glad to hear it's improved greatly. But they did, it was quite dominated by laypeople.

**PD specialist 1:**  
OK.

**P01:**  
Umm, that was the first thing I was going to say. And this is very difficult. I still find it difficult going around their website to find material on a particular topic.

**PD specialist 2:**  
Umm. (nods and agrees)

**P01:**  
I’m faced with a 10-year old blog.

**PD specialist 1:**  
Umm.

**P01:**  
Because Parkinson’s mentioned a particular symptom and I think it neds more work done. One thing that did work, in a very limited way, was they set up a program called First Steps. And their aim was to see everybody diagnosed with Parkinson's within the first six months. But they didn't do the arithmetic. We would have required hundreds of volunteers to actually run this course, which was people like me, working to a prepared script telling them what the early days would be like and where they could get help. Now it did work, but they couldn't administer it.

And (hospital) ran a similar system. But they couldn't afford the staff to do it because they were bringing the physios and the neurologists and the geriatricians. But that failed as well. They're both good ideas. Because you're seeing people face to face, but I think it's probably in the “dream on” category.

**PD specialist 1:**  
It's a shame, isn't it? Cause courses like those would be, you know, patient education courses and things like that are a brilliant way to do things. It's just trying to work within the parameters of commissioning and time, and you know all the NHS treacle that we have to wade through to do anything.

**PD specialist 2:**  
I mean, we used, we used to run those courses and they were, yeah. And OK, we, you know, we would have like a I think it was a eight week program and so we roll it through the year. So we'd wait till we had enough people to make you know so that because actually if you get a group of people it becomes very time efficient because you're dealing with maybe 10 people at once rather than one person. And we had we had physios, occupational therapists, speech therapists, dietitians, pharmacists. everybody used to come along and it was really good because you've got a whole group of people who had just been given a diagnosis, who again got to see that they weren't alone, that other people had the same things and also the fact that some of the problems they were having other people had solved them and had tips to share.

**PD specialist 1:**  
Yeah.

**P01:**  
Yes.

**PD specialist 1:**  
Why did that would end (PD specialist 2)?

**PD specialist 2:**  
It ended because they got when, when we lost, when we lost the ward sister who was in charge of the day hospital, who had the interest in Parkinson's, the new Commission, the new provider of the service wasn’t interested in it. But it used to be really good.

**P01:**  
Was the same at (previous hospital). You needed one individual who was fanatical about it to get everybody else on board.

**Moderator:**  
Yeah.

**PD specialist 2:**  
You know, we even had, I think one of the sessions was one, one of us turning up as a doctor to, you know, just a general Q&A of what, what do you want to know? What have we not told you that you want us to know? I mean, I do find. I don't know how it is for, for you and your part of the world. But I do find that our (local area) Parkinson's UK group are an incredible resource for people. And we always give out the details for them whenever we see anybody and think that they have got Parkinson's because they, they run all sorts of extra stuff like conductive education and speech therapy and singing courses and holidays away and all sorts of stuff that I met think makes it a social mornings that make a real difference for people with Parkinson's and their relatives cause the relatives are allowed to come too.

**P01:**  
There are two things I'd like to add very quickly.  
The first one is that the groups are my experience tend to split into two. There are those who people who want activities like speech therapy or physiotherapy, and then the ones who just want company.

**PD specialist 2:**  
Yep.

**P01:**  
It’s getting out of the house, its having a fish and chip supper.

**PD specialist 2:**  
Yeah.

**P01:**  
Having someone to come along and talk about their holidays in Greece or Italy.

**Moderator:**  
Yeah.

**P01:**  
I haven't reached that stage yet and I feel very guilty that I haven’t joined the group of people who do need it. What was the second thing I was going to say? Yes, an interesting thing that came out of the few first steps courses we did run, was on the second day, we split the People with Parkinson's, from the carers and discuss the problem of them in separate rooms.

And they had completely different agendas. And what was very interesting was we found that a lot of the time with the carers, we were turning into marriage guidance counsellors. The underlying problems were nothing to do with Parkinson's. They were all to do with relationships.

**Moderator:**  
Yeah, yeah.

**PD specialist 1:**  
I think that's the same could be said of any chronic condition. Actually, that's a very good point, yeah.

**Moderator:**  
Yeah. Yeah, it's not just the condition itself. It's how people cope, you know, as a patient and as a family and certainly that helps cope with everything, not, not just one thing. So I think what I'm hearing is for information, Parkinson's UK is a good resource, if signposted to the right things at the right times and you know for the right reasons. Not all of them are helpful and obviously. But I'm hearing that you know courses, so this information courses the first step courses with an MDT team that used to run has been very helpful in the past just to have that support and access to information and the ability to ask people questions about what they needed. And so that's been helpful.

So I think the next issue really is to do with prescriptions and medications, which I'm sure from all of your experiences is one of the big issue or can be a big issue for people with Parkinson's because you know the predominant mainstay of treatment is with dopamine, you know, to try and get optimal symptom control.

And one of the issues that we notice or from our interviews and surveys was about prescriptions. So difficulties getting the right prescription again probably due to the lack of communication at times or from PD specialist to the GPs and then when it gets to the pharmacists. And that sometimes that can be quite challenging to solve for the person involved. So I don't know what your thoughts are about how we can improve this, with this issue with prescriptions really.

**P01:**  
Well, I've had that personally. I've had no problems.

**C01:**   
Yeah, I was gonna say exactly the same. I we haven't had any problems with either prescriptions. Yeah, none of this. I was surprised to read it, if I'm honest. So I can't really speak to this. It's yeah, we've we've been, we've been good over here.

**P01:**  
Yeah.

**PD specialist 1:**  
Yes. Next question (Moderator), next movie.

**PD specialist 2:**  
No, I think I think no. I think it's a we I'm sure (PD specialist 1) would agree it it's for some people it could be a nightmare. And it depends upon depends upon lots of factors. I think how we communicate medication changes to GP whether the GP, how the GP writes the prescription, whether the prescription goes straight from the GP to the chemist without anybody in the middle.

And particularly for me, when as soon as somebody's in, like, a blister pack trying to change medication is just a nightmare because, you know, they've got a months worth of it. You want to change it. The pharmacist doesn't want to remake it. The GP doesn't want to reissue the prescription. And actually, sometimes I think it's a real problem for people and also I've had seen quite a few prescribing errors where people have had modified release when they should have had standard release or various Parkinson's medication put in.

All the doses being incorrect. I mean, I think the medications, the way some of them are prescribed, there's a lot of scope for error at multiple stages. And one of the nice things, one of the few nice things of when the service changed in (local area) was that we actually, I actually got given an FP10 pad. So I could actually write the prescription for the person there and then so they could actually start their medication that day, tomorrow if they went to the chemist as opposed to having to, you know wait for a GP, either me to fill in a GP medication sheet which then gets treated like a repeat prescription, so you're talking five days plus. Or the GP you know, getting it in the letter.

**P01:**  
Well, that's it. That's the procedure I've found at (hospital) and it works well there.

**Moderator:**  
Yeah.

**P01:**  
You I haven't had anything from (PD specialist) since she started there, but (PD specialist), just write out the prescription on the spot.

**Moderator:**  
Yeah. And then that's that's a prescription you will drop at the GP's tend to be usually, yeah.

**PD specialist 1:**  
Yeah. It's not an FP10.

**P01:**  
Yes. Yeah.

**PD specialist 2:**  
Where as we’ve got enough FP10s.

**PD specialist 1:**  
And then I think the non-urgent treatment request do work well. I haven't had any problems per say. It it does involve patient dropping off to the GP or their carer which you know, in an ideal world this would obviously be done electronically. And well, I often stress to the patient and their carer there if I am changing the medication, is that to the most part, it's not urgent. So just because I've made the change today don't freak out, you're fine on what you, you've been fine for the last couple of months on what you've been on. This can filter through over the next 2-3 weeks without, You know without. Because otherwise they think, “Oh I've seen the consultant. They must change it today.” And then they get hit up with the GP because they haven't done, you know, and it causes angst when it needn't necessarily. And a lot of that's about expectation setting.

Which you know, but I ideally it would be an electronic system, where you'd say, you know, this is what they're they're on. I mean, CHIE. The shared communications system, where I don't always look at it for every patient. I only tend to look at it if the patient's got an element of cognitive impairment and I want to double check what they're on. Because I was stung quite early on when I took over the clinic. I checked a patient's history, their drug history, which was on a letter that (PD specialist), my predecessor, had written.

I said to the patient, “I understand that you're on, blah, blah, blah.” They said yes. They were undertreated. So I increased it. But actually, what was in the letter originally, what (PD specialist) had put in her letter was incorrect. They were on less than that. So the increased, I prescribed was a huge increase, not the small increase I believed I was making. And then they, you know, had sequelae from that, that weren't serious, but.

But that needn't have happened had there been an easier way for me to just double check what they were actually taking and not the way not taking their word for it at that point in time. But that's, you know, that was a one off, really that doesn't happen all the time, but you know.

**Moderator:**  
Yes, C01.

**C01:**  
I would say though, this question about what patients are actually taking, if you asked either of my parents what they were taking, you would get quite a mixed response to pending on whether it was morning or the afternoon and really how tired they were. And I've, I've ended up the only way I could do this is I have a photograph on my phone of a letter that (husband) translated for me that I should explain my husband's also a doctor. So he took their medications, gave me the kind of keynotes and I've got it photographed on my phone because otherwise nobody seems to know everything that they're taking absolutely reliably. I can get a bit worried sometimes, cause it's seriously if you ask my parents.

**PD specialist 1:**  
Yeah.

**PD specialist 2:**  
Umm.

**C01:**  
Yeah, it would be a really interesting answer. I'm not entirely sure it would be accurate at all, and and then you think, golly. So yeah, it would be helpful asides from just the Parkinson's element. It would be good if you could go. I ended up wanting a kinda card like a, you know, like my Sainsbury's nectar card. If I could just have a card for each of my parents, please, with all up to date medication, if you could just have a card reader.

**Moderator:**  
QR code scan with the prescriptions that popped up.

**Moderator:**  
But I but I think you know part of that also comes into capacity actually, you know some of the aspects of how do people cope with this and and what makes it easier for some people. And that perhaps there's a like, you know, P01 and C01 saying they haven't had any problems, but actually what it is that you guys have that that means that it's easier for you to cope with it and not have problems compared to others. And that could be actually your experiences from the past and how your previous occupation or what you've done or other experiences that have helped or that you know I can get my prescriptions delivered that reduces that extra element of going to the chemist.

**PD specialist 2:**  
Yeah. No, I don't know. Have you seen the? Have you seen the… I know there's this whole new thing that that people with Parkinson's are gonna be given at certain app developed at the University of (name). But there was a there was another app that surround at the moment from a I think it's called a company (name). And one of the things cause I was exploring whether or not we would we would try using that, because they were offering it to us free for a trial because that that it's a subscription thing.

Where as well as doing a lot of the features of meals app, of terms of you know, measuring if people are freezing, what what their functions like and everything and then being able to do a test that you could test with bradykinesia and then it just gets emailed to your specialist. It also had all their drugs on it, and actually the clinician could adjust it from their computer at work. Any changes immediately, so it was on there on this app on the phone. I thought that was really interesting.

**Moderator:**  
Yeah. Yeah. Fascinating. (C01)

**C01:**  
Umm, but it immediately an age limited thing.

**PD specialist 2:**  
Oh, absolutely, absolutely.

**C01:**  
See I would. I would love that, but I would end up needing to carry the information for both of my parents who couldn't, couldn't do that at all. It would alarm them.

**Moderator:**  
(P01)

**P01:**  
The one thing that does worry me, I think, is if I was admitted into hospital in an emergency. How would they know what medication I needed? I carry a card with me and my wallet, which I've typed out myself. But would anybody go and look for it? No.

**C01:**  
Yeah, (P01), I have exactly the same concerns with both my parents. Yeah. And my dad has done exactly the same. I have a thing in his wallet that says what medication he's on. But would anybody go and look for it? Yeah, I completely agree.

**P01:**  
You know, I carry a day's supply around with me, but blue tablets, white tablets, brown tablets don't mean anything.

**C01:**  
Exactly. No, I completely agree.

**PD specialist 1:**  
I would say as by way of reassurance, I work also in the acute admissions unit and we do go rummaging around in wallets.

**PD specialist 2:**  
We do, we’re nosy.

**PD specialist 1:**  
The other thing I mean I you both will have received letters. I always write all of the drug history of patients, not just their Parkinson's bit. So that if you're the last clinic appointment be it a rheumatology appointment or PD appointment, all the drugs are there. which I know not everybody does or sometimes just deal with cardiologists or just write the cardiology drugs and forget the other bits, by way of example. And obviously the letters all go to the patients and their carers, and if that's not correct it you know it would it's some of the owners.

You know, I don't want to parent people too much. If I, you know, if, (P01), if you received a letter and it was incorrect, I'd expect you to tell me it was incorrect. Because if you come to hospital, incapacity, as someone will look at the last clinic letter, and go off that.

**P01:**  
That's right, yes.

**PD specialist 1:**  
But I had a patient recently that just said I don't read your letters. Ohh. Fair enough. I won’t take it personally.

**Moderator:**  
Yes, (PD specialist 2)

**PD specialist 2:**  
I just want to say again, though, that comes back to whether or not that is all joined up. So in hospital, all our clinic notes go onto the (name) health system of (Health system name) and no clinician at (hospital) or someone who's not to (health system name) access can access it. So for me, I completely get where P01 and C01 are coming from. Because when people come in through through the front door, if they're not able to say their list, people have no idea because the last the last clinic letters for my group of people that.

**PD specialist 1:**  
They don’t go on to CHIE?

**PD specialist 2:**  
They don't go onto CHIE either (PD specialist 1), it's a real issue. And so people are looking at letters that I wrote in 2015, which are obviously ages out of date. So there is something again about how we join up that communication because it's.

**C01:**  
We certainly we've I've had problems here because (hospital A) doesn't talk to (hospital B). So I live in (city). My parents are in (town), they've had admissions to both accounts in hospital A and hospital B and (hospital A) doesn't talk to (hospital B). I I had, I had to provide that. There was a different story, but yeah, they’re very close physically. They're so close but because they're different health authorities, suddenly A does not talk to B and no they can't see the X rays or the clinic results.

**PD specialist 2:**  
Yeah.

**PD specialist 2:**  
No, I I had that with.

**C01:**  
Ohh. OK, not so not so useful.

**PD specialist 1:**  
So the shared Hampshire health records, the CHIE system that is now getting better, you can access X Ray reports and discharge summary and letters from (hospital A) and (hospital B)

**C01:**  
That sounds like I wasn't the only person who's got seriously caught out between the two. Yeah.

**PD specialist 1:**  
Yeah. Tthere are all of these things are trying to improve, but they're not there yet.

**PD specialist 2:**  
I think I think.

**PD specialist 2:**  
I think the other thing we haven in (local hospital) is we have, you know, we have pharmacists who areactually based in the emergency department on the acute medical unit. It’s one of their roles to prioritize people with Parkinson's and actually get all the access to the medication. So certainly in the emergency department in (hospital), medication gets written up on a regular drug chart the moment they come through the door. And it's obvious that they're staying in.

**Moderator:**  
Yeah, yeah. So some aspects about communication there, as always with prescriptions and that communication errors. And I suppose moving on to the next one is about medications, you know, so issues that people have Parkinson's and caregivers have is about the frequency of medications, remembering to take their medications or, you know, any changes in the timings. And I don't know how you think this experience can be improved. Obviously, based from your experiences, because we do have some complex regimes for our patients. And what you think will improve this?

**PD specialist 1:**  
Patients seemed to use, or the more tech savvy ones are starting to use their smartphones to remind them to take stuff, at certain times. the only caveat to that is much like, you know, when you read a text message and you're busy and you forget to reply, it's days later. They have a very similar thing where it will go off and they think, oh, I need to take my medication. And then the moment's gone and they'll forget. And but there are starting to be some tech solutions. Also again, PDUK send through that leaflet of all the aids you can get. And I was just having a nosy through that the other day and there's quite a lot of medicine, medicine prompts and little containers. So if you're out and about, you're not back at home. And watches that buzz when it's medication time. So there are some tech solutions. And frequency of medication is individualized and you know, you try and make it simple as you can, but that if it doesn't suit that patient's regime, then then they have to have a more complex regime to a certain extent. But yeah, I think tech solutions are improving.

**P01:**  
And I've got some. Not not sure if you can see it. I've got a red vibrator watch there, which can be set for 12 times a day. But I still got the problem that I'm busy working somewhere. Ohh yes, I'll do it. Certainly realise an hour and a half later that you haven't actually taken the tablet.

**PD specialist 1:**  
Yeah.

**C01:**  
Yeah, we’re relying on pillboxes at the moment, just for weeks worth, morning, afternoon, evening, not the simplest, but we haven't, we don't have any really complicated regimes with just morning, afternoon and evening, just the three. But I like the idea of a bracelet that buzzed actually, that would work for my parents, yeah.  
  
**PD specialist 2:**  
I mean pill, pill timers work. Yeah, I agree with you, (PD specialist 1). I've got quite a few people who've got pill timers for when they're on medication, 6 plus. Four times a day. But it then requires somebody to set it up for them. So it depends on the cognition and that's part of the issue I think but but yeah, I think the Parkinson's UK living aids brochure is fabulous for all the stuff you can get, yeah.

**PD specialist 1:**  
It's really good and.

**Moderator:**  
OK, so perhaps signposting people who are not aware of or aware of this you know to try and help them because as you said OK, I don't think there's things that we can do to improve the frequency at a moment with the medications we have to help with Parkinson's.

And you know, moving on, I suppose one of the things from our study is also looking at the role that caregivers have and certainly we've talked about that. But our research found that about 50% of caregivers experience high treatment burden, so the workload of healthcare, helping someone with Parkinson's. So I don't know what your thoughts are about how we can improve the experiences of caregivers who take over that responsibility and for the person with Parkinson's.

**Moderator:**  
(C01)

**C01:**  
So I would have said that the thing that would be most helpful is this ability to access someone. So I manage actually for both of my parents. I'm managing all of their appointments and all of their visits and therefore I get told all of their symptoms and anything they're struggling with. And the ability to know who to ring, and how to get access so that I can find out, Does their appointment need to be moved? Do they need a different appointment? Should I be taking them somewhere much more quickly? Can we wait? It's that level of who to get in touch with and how to do it? Sort of working your way through the NHS systems. And it's not always that I want a really quick appointment for them, actually. It's not that I need them to be seen immediately. It's fine that it's, you know, a month, it's six weeks. As long as I know that it's in the system, and I've flagged what was needed. And so I would have said that's probably my number one in terms of how I can help them. That will be most helpful for me.

**Moderator:**  
Yeah, should navigating the system of giving you information pattern of getting the system, yeah.

**PD specialist 2:**   
And I would add to that about just it also being all aspects of the system. So like accessing social care and therapists and stuff because I think so often people phone up and they just get given a number to phone somebody else who gives them another number to phone somebody else who or they don't even know that they can do it. And you know, certainly with my mother-in-law trying to access an occupational therapist, for example, was really difficult.

**C01:**  
Yeah. Yeah, I would agree with that (PD specialist 2). We've stumbled into this. So my father's Parkinson's has moved from neurology to elderly care. That has prompted a link to the older person's mental health team, and they have sent an OT. And and actually that whole link has been great and I didn't know the links existed.

**PD specialist 2:**   
Yeah.

**C01:**  
And in fact, the OT has already visited and been extremely helpful. So yes, I would agree there's there's quite a lot that I don't know is available. It's not my condition, and I don't research it. But when they're presented, actually that would be great. Yes, please. And so I've kind of stumbled into this. I don't know how you would do it if I if I hadn't kind of fallen into it. I don't know how I would have accessed it. Yeah.

**PD specialist 2:**  
That's one of the things my mother-in-law would often say to me is I don't know, you know? What must it be like for people who don't have their daughter in law, who at happens to be a doctor who does Parkinson's disease? Because? Because I obviously, I know. I know the potential route, but I don't think that is clear to people. And as you raised earlier, there are some people who don't have next of kins and families to advocate for them and access that sort of stuff.

**C01:**  
Yeah. I would agree. I do a lot of advocating on their behalf and certainly, Neither of my parents now could navigate hospital outpatient appointments. Just the appointments, never mind getting to the appointment. Someone that changed, they couldn't navigate it. Now without me. And if it's not me. It would need to be somebody else. Yeah.

**PD specialist 2:**  
Yes.

**Moderator:**  
Yeah. (PD specialist 1).

**PD specialist 1:**  
And so I think there's a couple of things I just and I said, I think it's about, it's about approaching the carer and the patient in clinic. Because clearly you want to be addressing the patient. So some patients with advanced Parkinson's disease have communication issues. It is very easy just to talk to the carer and they're sat there. So iit's trying to talk to them, listening to the carer but making the appointment about them. But equally, I always try to, obviously I've only met all my patients now once or twice possibly. And during the first time I met them, I made sure I clarified all their social history in terms of who they live with, package of care, etcetera. And we always just tried to touch base to that so I can clarify if anything has changed. And if it is apparent that the carer, like yourself (C01) is doing, you know, the lions share of the caring also try and say , “And how are you?”. Once we've addressed all the kind of patient related stuff also just addres that. And out of that comes you know you might open a massive can of worms and that that's fine.

And but the other thing I'd like to say is, is the patient. Well, a wife said something very powerful to me recently in clinic we previously discussed. She was clearly getting a lot of carer stress and we discussed I said “I think you need to get some care.”. just so that because she was still a real doer, running around, and she would go out for a run and find come back and find him on the floor. And and this sort of thing. And I said you need to be able to continue your life, he does need some care and with him there saying “oh I think I don't really want that”. But I said but you need your wife to look after you forever and she's going to burn out. So I, you know, and we discussed it together and the next time we came to the clinic, they came to clinic. I said, you know, “Have you got any care?” And they said “Yes, because you gave us permission to do so”, which I thought was such a I was like, well, it wasn't, you know, you can make that decision yourself, but it was just quite interesting that that was the only way it was gonna come about, by someone bringing it up. And just clearly made me overrun. Obviously. But. But yeah, it's just so interesting.

**C01:**  
I was completely agree with that it's. TFequently it's clinical professionals who give my parents permission to agree to things my sister and I have been suggesting. And I need. I need the person who isn't family to say, “do you know this might be a really good idea”. And it doesn't matter how many times I've suggested it previously. I need somebody else who isn't family to say it to them. Yeah, I it's absolutely true.

**Moderator:**  
Interesting. I think (P01), you had something to say earlier.

**P01:**  
Yes, I'm not sure it's really relevant, but one thing that's struck me from the very first course I did at (previously hospital) was newly diagnosed to the first steps which I did for Parkisnson’s UK was how easily the conversations get taken over by the carers. And the people with Parkinson are actually irrelevant. They're much better going off to the pub. Whether or not, I don't know if that is unique to Parkinson's as a health issue and whether people with heart complaints or whatever, their careralso take over their lives. But it’s quite remarkable.

**PD specialist 1:**  
I think it's lots of conditions, (P01), to be honest with you. And it depends on the dynamic of the relationship. I mean, my father’s not particularly unwell, but I know my mother dominates most conversations. They always use the phrase “does he take sugar?”

**P01:**  
Yes, exactly.

**Moderator:**  
Yes, that's that's interesting. And I'm just conscious of time in and just as a final question is about, you know, can you think of other ways to help people with Parkinson's and their caregivers, manager their overall health, other than the things that we've already discussed in some of that is, you know, access to information, access to healthcare professionals and having that extra support. But other ways that perhaps you've experienced yourself that we haven't really talked about.

**PD specialist 2:**  
I think access..

**P01:**  
Maintaining friendships, I would say is one thing.

**PD specialist 2:**  
I was going to say access to psychologists You know that when we've had access to a psychologist, that's made a huge difference for some people.

**C01:**  
Certainly in our situation, the access to the mental health team has been fantastic and has definitely made it quite a significant difference in a way that I don't think I expected that it would. Both in terms of treatment, but also in terms of this sense of giving permission. And saying that certain symptoms are completely understandable and then giving solutions and way around it. So yeah, along those lines

**Moderator:**  
Yeah. Interesting.

**PD specialist 1:**  
I think (Moderator) as well. There's, I mean there is a certain I think it was Parkinson’s UK again there was a thing about waving join up fees to gym, that sort of thing and you know if you could have patient with Parkinson's disease have you know half gym membership so they can attend you know classes or you know more of the private sector stuff making it cheaper for PD patients to access and would be really good.

**PD specialist 2:**  
I think some of the therapies for which there's evidence that would be great, wouldn't it? So like the PD dance that, you know, I know there's of course that runs in (town), but there isn't one in (city) direction. Or Tai Chi or some of the stuff which we've got some evidence that it really helps delay progress of the illness progression. I hope (moderator) that you’re including social care when you say healthcare, cause I think that's the other thing is it it's such a shame. I'd really like it if our MDT we actually had a social worker come along a bit like they do on the wards because I think that would.

You know one of the issues that I see all the time is that people I say, well, you need to contact you know, I think you need some care, some support. Here's the number for social services and just navigating that is, you know, that it would be nice to be able to slot people directly into know this is the this is this is the these are the people. This is the direct phone line number. You know you don't have to I mean I give a number that goes through to (Region) County Council which then eventually gets passed back to (local area). And you know I think sometimes actually getting the care is so hard because of all the forms that adult services have for people to fill in before they they’ll actually do stuff. So for me that would be a key bit to join up in the system.

**Moderator:**  
Yeah. So if is the end of thing else that we haven't asked that you know you think should be mentioned before we close up. Any final thoughts or reflection? It's been a great discussion today.

**P01:**  
I would be very cautious about basing any system or relying very heavily on the system that requires a smartphone. I have a great ability to wipe all my wives calls off her phone because my hand just twitches like that. Umm, I've lost an entire lecture on my laptop because I hit the wrong key.

**Moderator:**  
Yeah. So definitely thinking twice with technology and Parkinson's that extra added symptom of Parkinson's makes technology that much harder.

**PD specialist 2:**  
Or maybe making technology easier for people with Parkinson's. Cause you know that there are things you can get that help adjust you, you know, help you write better. For example. There must be ways that we can adjust computers to cope with tremor and moving a mouse cursor cause, you know, my mother-in-law, she had a Chromebook and she couldn't use the roller ball mouse or the drag pad mouse, she needed a proper mouse and even then it was still a nightmare and she’d often click about 20 times before she got the things she wanted.

**Moderator:**  
Making technology easy. Yeah, that's it. That's a good way of putting it. Yeah, that's.

**PD specialist 2:**  
Because I think that's the thing about it. You know, you look at all the people with, you know, really severe disabilities in terms of they can't speak, can't move their eyes and there's all sorts of technology has been adapted to help them. For me, there's something about technology being adapted to help people with Parkinson's too. It's a bit like with all the, you know, a lot of people I know who the ladies do crafts, things like knitting and sewing and stuff. There must be ways of adapting it so that they can continue doing that when they have Parkinson's.

**P01:**  
Yes.

**Moderator:**  
Yeah, absolutely. Yeah. Great. Well, thank you very much all of you for all your input and discussion date has been a great discussion. I feel obviously we ask that you keep any discussion here today confidential. I do really appreciate your time and participation in, in my study today, we will be sending you a summary of the results once with analysed them at the end at the end. So hopefully by the end of the year, if not early next year, you'll see some of the issues and some of the things that we've talked about and hopefully you know things that we can improve the overall experiences for people with Parkinson's and their caregivers. So thank you very much all of you for your time.