**STOP-DEM – Deprescribing for People with   
Cognitive Impairment**

Transcript for interview

**P04**

***Please refer to the key to abbreviations on the last page of this transcription***

***[Note from the transcriber: as the Respondent has a stammer at times, you will see throughout the transcript I have not transcribed the stammer words more than once ]***

**INT: So, firstly, we just want to talk through the photographs that you kindly took. Can I ask you, were the photos planned, did you plan what you were going to take the photos of, or did you just think: “oh, I’ll just take that” so, spontaneous?**

P04: I was looking at these thinking: “how can I make this easy to fill-in?” because to, to keep on track as to what I’m trying to show, and so, I decided just to do it by pictorial, pictures just to show what the medication administration meant to me. So, on photo number one you can see that you’ve got my finger pointing at various tablets.

C04: That’s my hand, isn’t it?

P04: The hand is (*C04*)’s but it shows that it brings the tablets over and she administers them to me and she checks to see that I’ve swallowed them because sometimes just saying: “go and take your tablets, (*P04*)” ends up with me going to take the tablets (*C04*) might be distracted on something else.

C04: Haven’t done that for a long time.

P04: And I would go, forget to take the tablet. We changed the way we were doing things to more strategically getting (*C04*) to actually physically give and check the tablets because that way was more reliable and to have me involved in any part of the chain was, was no more or less difficult but if I was involved in the chain, I was likely to lose track of what I was doing. So, it was means of keeping an accurate record.

**INT: So, that’s (***C04***)’s hands handing you your tablets.**

P04: Yeah.

**INT: With your glass of water ready for you to take them.**

P04: Additionally, there I can see it hasn’t come out or it didn’t get done, the use of a Dossett box to remind us both to, what the actual dosage was supposed to be to keep the accuracy.

**INT: So, the tablets are put out into a Dossett box. They might be on (*C04*)’s pictures.**

C04: I’ve got a Dossett. They’re on mine. It’s on mine.

P04: So, essentially, I took little or no responsibility for organising or giving or taking the tablets. I think, (C04) preferred, preferred to maintain control of that because she knew that I would miss tablets otherwise and that would negate benefits of a tablet’s nature so.

**INT: So, what about photo two?**

P04: The walking stick?

**INT: Uh hm.**

P04: There’s a slight loss to remember what, why I, because the walking stick was the main object of the tablet as far as I was concerned, was walking accurately and taking accurately what made it easier for me to keep track of the tablets. This is taken in our bedroom and shows the stick is the dominant treatment.

**INT: Do you take any tablets in your bedroom?**

P04: There are tablets which I take both upstairs and downstairs because the tablets are kept on the Dossett box on the windowsill and (*C04*) would collect them and give them to me wherever I was in the house at the time. So, removing…

**INT: So, that’s primarily downstairs?**

P04: So, it’s removing me from the loop of responsibility essentially to ensure that accurate dosing was given.

**INT: And what about photo three? That looks like it might be breakfast or a meal or something.**

P04: It is with breakfast ...

C04: It’s breakfast, isn’t it?

P04: Yeah, that’s breakfast which is eating a protein supplement in addition to ordinary cereals and, I think, for number three, the, it starts with me having a breakfast cereal although I had several choices of different cereals that I could choose but that is the other element of what I was being treated by was (*pause*) the Dossett box to give the tablets from. A stick to get me to the tablets and at an accurate time and three a measured quantity of protein nutrition and general food nutrition.

**INT: So, do you take a lot of medications at breakfast? Is that a significant time?**

P04: There’s five different…

C04: So, it, really after that, I think, he has his breakfast and that’s the reminder that he has his tablets, and he has, you have four, don’t you, after, for, but we always like him to have eaten before he has his tablets.

**INT: So, that’s the significance of the breakfast?**

C04: Yeah.

**INT: Is there anything else that you do to manage your medication or is it primarily (C04) that does everything else to do with your medication?**

P04: It’s primarily (*C04*) does everything and also orders me to try and do physiotherapy exercises as part of the (*laughter*), as part of the general tablet taking management.

**INT: So, she kind of keeps an eye on everything and prompts you to do things.**

P04: Yeah. So, I know that I’m meant to be taking tablets at various times, which tablets they are, I rely on (*C04*) to actually remember what they are and the Dossett box ensures that accurate administration is given regardless of who’s giving the tablet, if they follow the box, accessing the tablets, taking out the tablets which are needed and giving in the moment the four or five tablets that were needing to give at that time, at that particular time.

**INT: So, correct me if I’m wrong, what helps you is (*C04*) and the Dossett box.**

P04: Yeah.

**INT: So, they’re kind of two really helpful tools.**

P04: And other than that, the walking stick and the Dossett box and (*pause*) a regular routine are what essentially maintain accurate medication prescribing.

**INT: And do you face any particular challenges with managing your medication?**

P04: Well, yeah, it’s difficult to get to the medication downstairs or upstairs, I have to make my way to wherever that is or (*C04*) has to come and find me and if it’s me, I may forget to take the walking stick with me which is a danger because I get a stagger, I call it, both sides of the body stagger together, and cause me to trip up. I think, it’s called hemiballismus, is the proper term for it.

C04: You sort of freeze, don’t you? And then he can’t get going.

P04: Yeah, I freeze and then I feel myself gets going, how to get at least one foot off the floor to sort of push off and get me across to a hand-hold, to catch-hold of, so, it’s a bit athletic but nothing more than that.

**INT: So, the biggest challenge is getting around and actually getting to a place where you can take your tablets?**

P04: If I’m taking a walk, I can walk a good distance because it doesn’t, the manner of walking for reflex walking is different to the manner of walking for more targeted and it’s a feature of the difference between (*pause*), forgotten it.

**INT: That’s fine. So, when we were filling out your form you said that you take six regular medications.**

P04: Yes.

**INT: How do you feel about that number of medications?**

P04: If it’s what is needed, it’s what is needed, but it’s important to review that to be sure it is needed and so, reviewing the effect of the tablet, of the tablets individually, but I can’t keep track of that personally because I don’t hold it in the memory so, you rely on the dossset and…

C04: We do talk sometimes, don’t we, sometimes we have a conversation about each medicine and how does he feel it’s helping him, and obviously, do I feel it’s helping him as well, you know. So, we do talk from time to time, don’t we, about medication.

P04: I find it quite difficult and quite uncomfortable wherever I happen to be to sit down and take details of that because, again, as a physical feature of the tablets on the benefits, side-effects can often cause trouble. Sometimes, I’m a little uncertain as to what’s side-effects and what’s therapeutic effect.

C04: Is it your condition. Yeah.

**INT: So, what’s to do with the condition and what’s the side-effect. Yeah.**

P04: So, we tend to be fairly reliant in terms of what we take is what, we take what is ordered and review that at medical review.

**INT: So, talking about a medical review, do you remember a time when you’ve actually had your medication as a whole, so all of your medications, were reviewed?**

P04: About once a week we tend to go through all the medicines, you know, we’re seen once every month or so with the GP who reviews what we’re taking as well.

C04: Can I interject there?

**INT: Yeah, please do.**

C04: We did have an appointment with the pharmacist, the practice pharmacist, didn’t we?

P04: Yes.

C04: I mean, I can find you a date for that if you want it, but it was a few months ago.

**INT: No, a few months is fine.**

C04: And actually, because we’ve now, in Sinemet, a new drug has been introduced fairly recently, we’ve actually had fairly regular appointments with the GP over the last, about, you know, a couple of months where he’s seen as reg-, to make, to, to assess how the Sinemet, you know, is it helping or, or not. So, we’ve, recently, we’ve had fairly regular contact with the GP, haven’t we?

P04: Yeah.

C04: And we had the review with the pharmacist about…six months ago.

P04: ... we also had quite a lot of, between us had quite a lot of quite intense evaluation of what side-effects we were getting.

C04: Yeah, we do like to talk about it.

P04: I was concerned about constipation and continence at night, how one could control that, and the actual effects of stagger, staggering through walking, and the dangers of falling if I forget to use my stick to get from one part of the house to the other. It’s the walking through doors and thresholds creates quite a problem particularly, particularly actually I discovered going into the kitchen because it’s quite a narrow door. So, that’s…

C04: Yeah, that, and also, I, we were reflecting, something they mentioned when we went to that physio appointment, that change of colour on the floor. So, you can cross a threshold from our hall, you go from a carpet to a tile, it’s a pale coloured to, to a brown colour.

P04: Yes. Yeah.

C04: And, I think, that really affects him. That awareness that, you know...

P04: Because even if I approach fairly slowly, I slow down and try to turn the corner at a steady pace, but I very often fail on that one and end up sort of charging (*C04*) in the kitchen (*laughter*).

C04: Had so many near misses (*laughing*).

**INT: So, in terms of those discussions that you’ve had with the pharmacist, with the GPs, have they ever recommended any changes to your medication that you can remember?**

P04: Yes, we saw a doctor who is a consultant in the field to take stock of what we were currently…

C04: That was the pharmacist.

P04: What we started to take.

C04: So, this week we saw the doctor and we’ve reduced the Sinemet, haven’t we, because it, his blood pressure was dropping quite a bit, and before you started the Sinemet, we actually had a conversation because the, the reason we started it is because we felt your Parkinsonian symptoms were getting a bit worse, didn’t we?

P04: Yes.

C04: So, that, because that’s a fairly recent addition, the Sinemet.

P04: Yes.

C04: And the others, he’d been on more long-term, but I would say they’re quite good at asking us about whether we, you know...

P04: We go through the…

C04: So, we have been through with a GP and with a pharmacist, haven’t we, fairly recently, the medication you’re on.

P04: He keeps taking, taking control of the list.

C04: Yeah. So, he’s been quite good really.

**INT: So, would you see stopping or reducing medication as a normal part of managing your health conditions or would you see it as something that’s a bit unusual?**

P04: Well, it’s something which I expect will probably require additional or changed medication in the future, but we have at the moment a tablet for controlling tremor and another for controlling blood pressure and another for controlling, the Sinemet is a dual therapy which in itself presents its own side-effects, and one or to two others which I can’t recall to hand without actually looking into the paperwork we have.

**INT: So, you’ve listed a few there. Are there any of those medications that if somebody was to suggest that you stopped, or reduced, you’d have more concerns about stopping or reducing?**

P04: Yes. Yes

**INT: So, which ones would you have more concerns about?**

P04: In terms of symptom relief, medication for tremor and I’ve given those, it’s Sinemet. Seems to be quite effective. Medication for anxiety and…

C04: That’s the Mirtazapine, isn’t it?

P04: Mirtazapine and Serotonin, not Serotonin umm…

C04: So, you’ve got your Rivastigmine. What do you think about that one?

P04: Rivastigmine.

C04: What’s that one for? That one’s actually for the?

P04: That’s for (*clicking fingers*) dealing with tremor.

C04: No. No, that’s for dealing with the Lewy body dementia, isn’t it, that one.

P04: It’s for the Lewy body dementia but…

C04: How do you feel about stopping that one?

P04: I would be concerned about stopping that because I see that as something which is holding it back, but the other the long-acting anti-depressive.

C04: That’s the Sertraline.

P04: Sertraline. Yes.

C04: Again, that’s a fairly recent one, isn’t it, that we’ve tried.

P04: Recently I did and, I think, that has quite variable symptoms (*mobile ringing*).

**INT: So, it sounds like the ones that would be of most concern if somebody suggested stopping it is the one for the dementia and the one for the tremor?**

C04: See, I’d go further than that and say…

P04: Tremor and Mirtazapine. Tremor and…

**INT: And the Mirtazapine?**

C04: The Mirtazapine. Yeah.

P04: The Mirtazapine for anxiety and worry, and…

C04: I think, the Sertraline is the one we’re not absolutely sure it’s made a huge difference.

P04: I’ve currently got a big problem of waking about three in the morning and not being able to sleep for the rest of the night which is getting me very exhausted and that gives me a concern and also, it might be representing a progression of symptoms which I’m waiting to see as time goes by whether that’s something which might need to be altered in some way or other. But the Sertraline was dropped by…

C04: No, the Sinemet.

P04: The Sinemet was reduced by one tablet out of three, three per day to two per day. That’s not really helped very much.

C04: Well, that’s literally, literally only this week, isn’t it? So, it, literally, that was on Monday so, we, we can’t, that’s because his blood pressure is getting a bit low.

P04: I see it as a dynamic thing which is changing from day-to-day sometimes.

C04 (speaking softly): Yeah, it’s all down, isn’t it?

**INT: Yeah. Do you remember a time when any medication has actually been stopped so, stopped completely?**

P04: We did stop one which was, which I can’t remember.

C04: The statin.

P04: Oh, is it? Oh, various preventative doses. Then there’s, Simvastatin.

C04: OK, you’re on Atorvastatin until about two months ago?

P04: It’s Atorvastatin, we, that’s been stopped as being non-effective in…

C04: Well, not necessary. No.

P04: This late in the day.

**INT: How did you feel about stopping that?**

P04: OK because it’s a, trouble with a few side-effects specifically and it helps in terms of represent, of controlling thought processes, perhaps keeping me more settled in my mind. And the Aspirin, not Aspirin, Clopidogrel. That’s, for managing clotting factors in case of the effect that it has on…

C04: We were concerned about, because you had your TIA, didn’t you, and you had two little strokes.

P04: Oh the TIA so, with the history of strokes and the TIA…

C04: They want to keep him on that.

P04: I must stay on that, but it’s very free from side-effects, just the odd shaking.

C04: You’ve been quite fortunate on the side-effects generally, I’d say.

P04: Sorry?

C04: Would you say on--- on the whole, side-effects, you haven’t been too troubled by?

P04: No. Yeah, some of it I would, yes.

**INT: So, the statin is the only one that’s been stopped completely.**

C04: Yeah. Yeah, and that was in October.

**INT: And were you involved in the decision to stop it?**

P04: Yes, I think so.

C04: Yeah, I’d say we were.

P04: Because…

C04: We discussed it with the GP, didn’t we?

P04: Yeah, we had a few discussions about which tablets were worth staying on and stay--- and stopping. Yeah.

**INT: And after they stopped it, was there any follow-up about any changes?**

P04: There was as part of the follow-up in the community health clinic.

C04: Yeah.

P04: We’ve been attending for …, community health.

C04: We’ve not been attending any community health clinic though.

P04: Dr, Dr…

C04: We went to see the physio, didn’t we, a couple of weeks ago.

P04: Yeah.

C04: Are you thinking of that?

P04: No, Dr (*name of doctor*).

C04: Oh, we’ve not been there for a long time. We’ve not seen her. She discharged us.

P04: But she was involved in making some of the…

C04: Yeah, but we’ve been discharged from her care in July, I think (*shuffling papers*), didn’t we?

P04: Yes.

C04: That’s the elderly person’s mental health consultant, and that was in July. We were discharged when he, she requested that we just went to the GP.

P04: In the run up to this, we’d been seeing a lot of different specialists to confirm that it is, thought a Lewy body type dementia with the brain scans involved...

C04: Lots of scans actually.

P04: ...isotope scans. None of those have really revealed any particular feature that give reason to change things.

**INT: So, now it’s primarily your GP and primary care who are overseeing everything?**

P04: Yes.

**INT: And making those decisions with you.**

C04: Yeah.

**INT: So, thinking about perhaps a point in the future where another medication might need to be stopped or reduced, how do you think those decisions should be made?**

P04: With the presence of (*C04*) and myself, and the consultant or senior…

C04: GP?

P04: And the GP taking a part in controlling symptoms, symptom review.

**INT: And would you see that as something that needs to happen face-to-face or is it something that could be done over the telephone?**

P04: I think, it’s--- it can be done over the telephone in different circumstances, preferably, preferably with some sort of review of that within a reasonably short time scale to confirm that the change has been effective or or benefitted.

**INT: So, you’d like some sort of follow-up afterwards?**

C04: Yeah.

**INT: To check how things are going.**

P04: To keep a finger on the pulse, so to speak because, where things are going. I’m, I mentioned about the side-effects of sleep problems at night and that’s given me quite a fair degree of concern because it makes me worry that the symptoms are progressing quite quickly.

**INT: So, just having that follow-up to say: “this is worse” or: “this is better” so that it can be reviewed?**

P04: Yeah, it’s: “what happens if?” is quite often the sort of question that I would ask.

**INT: So, that was going to be my next question actually, if somebody was to suggest to you to stop a medication, what questions would you have? What information would you want?**

P04: Why, when and any doses and effects of the tablets taken over a period of time to see that the treatment is effective.

**INT: So, your questions would be why are they stopping it, when do they want it stopped?**

P04: Yes.

**INT: And you would want yourself, (***C04***) and either the GP, or the consultant, to be involved in that discussion?**

P04: I think so. Yes, we have PIP.

C04: Your PIP? Yeah. Yeah, that’s that’s more to do with, that’s the sort of financial side of it, sort of having support for care for you, isn’t it? It’s because I’m having to be here.

P04: What action to take when…

C04: Oh, your advanced decision?

P04: Advanced decision. Yes.

C04: And your DNR.

P04: And DNR. So, we have those in place to discuss in the future if the need seems to be arising.

**INT: So, you’ve been doing quite a lot of planning.**

C04: We discussed that at the early stages really. We I think, again, because we’ve got backgrounds, you do think about these things and you want to plan them early while you can actually, when you’re sure that the decision you’re making is, is the decision, is, that he made, made for himself.

**INT: So, in terms of having those discussions with a healthcare professional about stopping or reducing a medication, what things make it easier for you to feel like it’s really shared decision-making? So, you’re really involved in that decision-making. Is there anything?**

P04: Well, effective medications the most important thing and that’s sadly something which isn’t widely available yet and the condition is progressive and treatment of it is limited but benefit, but it is doing the best in the face of an adverse situation.

**INT: And in terms of which professional is it, is there anything that makes it easier for you to have that conversation with the professional?**

P04: I think, a good relationship with the GP who is on-board for arranging, prescribing without delay when required and a clear consultant lead. Not necessarily treating but overseeing the condition as it goes.

**INT: And so, you’ve got a good relationship with your GP? Do you see the same GP?**

P04: It has been changing around a little bit because of the changes in medical provision in general.

C04: The last few times we’ve managed to see the same GP, haven’t we?

P04: Yes.

C04: He’s a, a locum GP but we have, say about the last four times consecutively now, he has, you know, very deliberately made sure it was him we see so that he recognises (*P04*) and…

P04: It’s mainly a discussion of side-effects and what’s to be done, is it satisfactory, and the answer has been: “yes” to that.

**INT: So, you mentioned (***C04***) being there at any of those discussions.**

P04: Yes.

**INT: Is that important?**

P04: Very important because she’s actually controlling most of the medication (*laughter*).

**INT: So, having her input is really important?**

P04: It is. Yes.

**INT: So, thinking about the medication that’s been stopped and we’ve probably talked about this a little bit already, but just thinking about what should be in place when a medication is reduced or stopped. So, you’ve mentioned follow-up, what should that follow-up look like?**

P04: A consultation with a medical professional, preferably face-to-face but if not, within a telephone setting with access to guidance within that telephone setting.

C04: I personally feel a telephone conversation for you is not really practical because…

P04: It’s not because I can’t…

C04: Because you lose your way on the ‘phone, you know.

P04: I lose my way, I can’t talk.

C04: I mean, you do a little bit but you, his words on the ‘phone.

P04: I can’t find the words that I need, and anxiety provokes a lot of…

C04: I would say, it has to be face-to-face.

P04: You know, side-effects that I, tension causes more side-effects, the tremor, to make assessment more difficult.

**INT: And you’ve already said that having (***C04***) involved is important and obviously, that’s more difficult on the ‘phone, isn’t it?**

P04: Yes. Yes, it is.

C04: I, I end up having to take the ‘phone conversation really. I, you know, realistically, I have to lead it really whereas at least if it’s face-to-face, it gives you that opportunity to, I feel, talk a little bit more.

P04: It is and being able to discuss things in a way that is comprehensive and comprehensible is difficult because, I mean, it’s a disease of limited knowledge of how and when it take its place and treating a disease with unknown aetiologies is always going to be difficult and frustrating because one recognises ultimately the outcome is not a good outcome depending on how you assess those things. That leads to certain tensions about when, where and what to do but ... and access for telephone consultation is essential to maintain the speed of access.

**INT: So, that’s all my specific questions. Is there anything you would like to add around your medication or stopping medication?**

P04: Not specifically. I think, the staggers and the continuing need to sort of watch out for that otherwise it might lead to a more serious fall in future, and we’re having changes made in our housing, a grab rail particularly.

C04: Oh, yeah, that’s, yeah, they’re coming on Monday, thank goodness.

P04: Yeah, and that’s due to, the banistering is quite satisfactory for what we use but could probably be extended somewhat.

C04: Well, we’re having the stair rails done, aren’t we, on Monday. An extra…

P04: It’s a stair rail so that they’re easily grabbed hold of.

**INT: So, it sounds to me like for you one of the biggest concerns is falling.**

C04: Yeah.

**INT: And therefore, any medication might add that as an additional risk is something that you would be concerned about.**

P04: Yes. Yes.

C04: Yeah.

**INT: That’s great. So, if there’s nothing else that you want to add, I can switch the recorder off. Yeah?**

P04: I think so, I--- like anybody under the hammer, so to speak (*laughter*), it’s a frustrating position to be in and there’s bound to be a certain degree of lack of satisfaction because of that. One has to sort of take that with a philosophical thing. We’re looking into getting more access to physiotherapy and group…

C04: Yeah, joining some groups and things.

P04: Joining groups to see if this has any…

C04: Just a sort of positive input, you know.

P04: Positive inputs to add to what we’re already doing.

**INT: Yes, sounds great. I will switch the recorder off now.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

P04 Respondent

C04 Second Respondent

***Audio* file: 34.42 minutes**