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

Transcript for interview

**P03**

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

**INT: So, we’re going to talk first of all about the photos that you’ve taken.**

P03: Yeah.

**INT: So, can I ask you first of all, did you plan these photos or were they spontaneous?**

P03: Well, maybe just spontaneous. I wouldn’t have--- I just set those out and took photos.

**INT: So, as it was happening, you just took them?**

P03: Yeah.

**INT: So, let’s have a look at that photo on the top there so, that’s photo number seven. Can you tell me a bit about that picture? What does it show?**

P03: Well, you’ve got all the containers that I put them in for a week. OK, she puts them in and those two there show the tablets that I’m taking. Well, they’re not complete ’cause I haven’t finished but that’s in the process of setting up the containers.

**INT: So, photo number seven is the pots and number eight is your wife’s hand.**

P03: No, it’s my hand.

**INT: Is that your hand?**

P03: Yeah.

C03: No.

P03: No. No, that is the wife’s hand because she, she’s got a ring on it.

**INT: So, she’s putting the pills in the different sections.**

P03: Yeah.

**INT: So, how do those boxes work? How do they help you?**

P03: It, well, I- I just take morning and they’re- then- then- yeah, that’s one there (*handling pot with tablets, tablets making noise when pot moved*). Yeah, that way. Morning, mid-day, evening and night. They’re marked so, I can just take those in the morning, those in the mid-day, those in the evening and those at night.

**INT: So, you know that you’re taking what you need to take?**

P03: Yeah. Yeah. Yeah.

**INT: So, that was photo number seven and photo eight.**

P03: Yeah.

**INT: Let’s have a look at photo numbers nine and ten.**

P03: Right, those are- those- that’s the- the container that I keep them in and I’ve got all the days of the week on there so, I usually set them up in the days of the week and then I take one out of the top of there and I just take the tablets through the day.

**INT: So, when you’ve finished with one of your pots.**

P03: It goes in the bottom.

**INT: Oh, it goes in the bottom of the stack as on photo number ten.**

P03: Yeah, I just- just turn that upside down and it goes in there *(pointing to the stack on pots labelled with days of the week held in a container shown in photo 10 and pointing out that the used container would be put in at the bottom)*. Yeah.

**INT: So, then you can just kind of keep…**

P03: But I just take a top one out during the day and it goes on the worktop in there *(indicating the kitchen)*, which I take the tablet from during the day, and then at the end of the day, it goes in the bottom of there and I take the top one off. Yeah. Yeah.

**INT: And how much support with that do you have from (*C03*)?**

P03: Well, (*C03*) does a bit of it but I- I could do that. *(C03 says she does it all quietly in background)*

C03: Yes.

P03: Yeah.

**INT: So, do you do that or does (*C03*) do some of it?**

P03: (*sigh*) I don’t know, (*C03*) does some or not. Yeah.

**INT: So, you kind of do it between you.**

P03: Yeah, it’s done between us.

**INT: So, I think, the last photos are very similar, aren’t they, numbers eleven and twelve?**

P03: Well, that’s showing the full container Monday, Tuesday, Wednesday, Thursday, Friday, Saturday and I- I just take the top one off and then when that’s finished, I turn it upside down and it goes in the bottom and that’s the next day, at the top.

**INT: So, for the purposes of the tape, that’s photo numbers eleven and twelve. So, around your pots with your medication in, is there anything else that you need to do to manage your medication that maybe doesn’t happen on a daily basis? Anything else?**

P03: No, not really. I mean, ev- everything is set out for a fortnight. I’ve got two of those (*Points to picture 11)*.

**INT: So, they’re done two weeks at a time?**

P03: So, I- so, I set two weeks at a time and they go in the cupboard in there *(indicates to kitchen)* and then in the morning, I can just open the cupboard up, I take the top- thing off the top of there, off- off whichever one I’m using *(indicating container holding the whole week’s supply)* and that comes out on the worktop in there *(indicating a pot for one day)* and then I take the morning ones, and the day, evening, night and so on and so forth, and then the empty one goes in the bottom and the- and the next one comes off for the next day.

**INT: OK, that all makes sense. So, is there anything else that helps you with medication taking?**

P03: (*sigh*) No, I don’t think so. I- I don’t- I mean, sometimes the wife gives me a kick, you know, with times, date and medication.

**INT: So, there’s a bit of verbal prompting going on as well? Yeah?**

P03: Well, no- no, it’s- it’s the foot more than (*laughter*)…

**INT: Oh, it’s the foot (*laughter*). OK.**

P03: No, it’s- it’s- it is verbal but (*laughter*)- I try to get her into trouble, you see (*laughter*).

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

P03: No.

**INT: No?**

P03: No. No.

**INT: So, it all plods along.**

P03: Yeah. Yeah, I take a big tablet at night which isn’t in there, but that’s about so big *(indicates with his fingers)*.

C03: That- there should be one there for this afternoon unless you’ve been and taken it.

P03: Oh, yes, there is.

**INT: So, it is in there?**

P03: Yeah. Yeah, it is in there. That’s that big one. Yeah.

C03: That’s tea-time.

**INT: So, all of your tablets are in there?**

P03: Yeah, they’re- they’re all in there. Yeah, I tell a lie (*laughter*).

**INT: That’s OK, you’re allowed to be mistaken (*laughter*). Not a problem. So, we established a few minutes ago when we were filling in the form that you currently take eight medications so, eight prescribed medications. How do you feel about the number of medications that you’re taking?**

P03: Well, I’ve been taking them for so long now that it really doesn’t bother me one way or the other. I just get up and I- I just take them. I mean, if I could do with less then, you know, I would do with less, but it does- I don’t feel like I’ve got to take more, I don’t feel like I’ve got to take less, I just take what’s in the container. Yeah.

**INT: And very used to taking them?**

P03: Yeah, I’m so used to taking them, I’ve taken them for so many years now that, you know, it becomes second nature. Yeah.

**INT: So, thinking about your medication and the lots of different medications that you take, do you remember a time when you’ve had a review of your medication?**

P03: (*sigh*) I think I did a long time ago but I couldn’t tell you when. I couldn’t tell you what year it was.

**INT: So, when we’re saying a long time, we’re talking years rather than months?**

P03: Yeah. Yes. Oh, yeah. Yeah.

C03: Yeah.

P03: Yeah.

**INT: Do you remember who it was who reviewed your medication? What professional?**

P03: (*sigh*) I assume it was done down at the- the surgery, I think, but I don’t know who did it.

**INT: No, I was thinking more was it a GP? Was it a nurse?**

P03: Well, I- I don’t know.

**INT: You can’t remember.**

P03: Well, it- I wouldn’t know. I assume they review it, but I don’t get to speak to anybody.

**INT: So, you weren’t involved in a review process?**

P03: No. No. No.

**INT: But you’re aware that your medications have been reviewed.**

P03: They had been reviewed (*sigh*)- I think, the last time was probably a couple of years ago.

C03: Oh, yeah, probably four.

P03: Yeah.

**INT: And then did somebody tell you that they’d been reviewed?**

P03: (*sigh*) I assume that I was notified that they were being reviewed, or had been reviewed, I can’t honestly remember.

**INT: That’s absolutely fine. It’s just helpful to know there has been some sort of review.**

P03: Yeah. Yeah.

**INT: And again, it’s OK if you don’t remember, but do you know whether any changes were made as a result of that review?**

P03: No. No, I haven’t had any- I haven’t had any changes in the medication I take (*sigh*), oh, for some time now.

C03: You have.

P03: The wife says I have.

C03: We’ll get to that in a minute (*laughing*).

**INT: OK, we’ll talk it through with (*C03*) in a bit so, that’s fine. So, sometimes when they do review medication, they may decide that something’s not needed anymore.**

P03: Yeah, and take it off.

**INT: And then then maybe stop it or start to reduce it.**

P03: Yeah. Yeah.

**INT: What are your thoughts around stopping or reducing medication?**

P03: It doesn’t worry me one way or the other. If they say, you know, I’m- I’m- obviously, I’ve been given these at various times, added another tablet. They say I need them, I take them. If somebody came along and said to me: “you don’t need that anymore” then I would stop taking it and it- it wouldn’t worry me.

**INT: So, would you see that as part and parcel of the normal management of your health conditions?**

P03: I would have thought so. Yeah. Yeah.

**INT: So, you wouldn’t necessarily see it as something unusual?**

P03: No. No. No, I- I- I assume that occasionally, somebody reviews it down at the surgery. We’re not notified when somebody is reviewing it but if somebody reviewed it and they told me: “you don’t need to take that tablet anymore”. In fact, I think, years ago, I did take a tablet which they stopped (*pause*) (*sigh*)- a little- what I called depth charge (*laughter*). I- I don’t know exactly what it was for, and they obviously decided I didn’t need it anymore with what else I was taking. I mean, I didn’t get all these tablets in one go, they’ve been prescribed over a long period of years, you know: “you need another one” and: “you need another one” until I don’t need breakfast (*laughter*).

**INT: So, thinking about that one that was stopped, were you involved in any discussion about the need to stop that, and making the decision, do you remember?**

P03: No, I don’t think I was. I was taken off it (*sigh*) (*pause*) (*sigh*) You know, I was trying to think what it was for. I know when I was put on it, they could tell me that it- they did tell me that it could have an effect on something else, but it is so long ago now that I honestly can’t remember all the details.

**INT: No.**

P03: And it- it- they took me off that, what was it, two or three years ago (*C03*)?

C03: Uh huh. Yeah.

P03: And can’t say I’ve missed it.

**INT: And what happened after they’d stopped it? Was anything further done?**

P03: No. No. I- I think, it was just a question of if I stopped it and I had some ill-effect from it, then obviously I would have gone to the doctors.

**INT: So, it was left for you to feedback to them if there were any ill-effects?**

P03: I think so. As far as I can remember, yes. Yeah.

**INT: And do you remember if that was the GP or, again, are you not sure?**

P03: It was somebody down at the surgery. Whether it was the actual GP that I see or whether it was somebody else down there that said they were reviewing tablets. I really don’t know.

**INT: And so, thinking about the medications that you’re currently taking, are there any medications amongst those that you would be more concerned about stopping than others?**

P03: No. They tell me I need them- if they tell me I don’t, fine, I don’t. But, you know, all the medication that they’ve told me I need I bring it up- it- it all comes in blister packs *(referring to individual medication blister packs rather than a nomad type blister pack)* and I put it all in these things and I’ve got a stack of those, I can do a fortnight’s, and I just take the one off the top and the empty one goes in the bottom.

**INT: So, you just carry on until somebody says: “don’t do that anymore”.**

P03: Yeah. Yeah. Yeah, if somebody says: “don’t take a tablet anymore” or takes it off the list, fine.

**INT: Do you think there might be any reasons why you might think: “oh, I really don’t want to take that tablet anymore?”.**

P03: No, I- I- I- I mean, I don’t feel, when I take the tablets it doesn’t change the way I feel or maybe it changes my or improves my memory or whatever, I don’t know. I mean, that’s the medic- the way medications work, isn’t it? It doesn’t sort of hit you over the head and say: “I’m working (*laughter*)”. So, I- I- I- everything that they’ve given me over the years or- or what I’ve been taken off over the years, I can’t say that anything has ever bothered me. Yeah.

**INT: So, if we think about maybe at a point in the future of when there’s some decisions to be made about potentially stopping a medication.**

P03: Yeah.

**INT: How do you think those decisions should be made about stopping or reducing medication?**

P03: Well, I- I would assume that the doctor would do that depending on how I felt. You know, if I had a- a bad turn, I assume that they would review the tablets that I’m taking. (*pause*) (*sigh*) As far as I’m aware, there hasn’t been a review of the tablets that I’ve been taking. I mean, I- they’ve been added to over a long period of time. I mean, I- Primidone is one of the ones that I’ve been taking the longest and that was for tremor in the hands and the others have been added to over the years for one reason or another.

**INT: And so, when you talk about your doctor, you’re talking about your GP?**

P03: Yeah.

**INT: Rather than a hospital doctor.**

P03: Yeah. No. No, GP. Yeah.

**INT: So, you would see the GP as being best placed to look at,- review your medication?**

P03: Yeah. Yeah, if I- if I was going to see anybody about a review or I, you know, I had a problem with any of the tablets, I would go to the GP. Yeah.

**INT: So, if it we recommended that you stop one of the medications, what questions might you have that you’d need answering before that happened?**

P03: (*sigh*) I might ask what that specific tablet was given to me for and whether or not then I would be aware of whether that came back after I came off the tablet *(‘phone ringing*). So, if it was given to me for shaky hands, for example, and (*C03 talking on the ‘phone*) when I came off it, I found that the hands were shaking so bad that I couldn’t do anything, then I would know that that was the- the tablet that I’ve come off and I would go back to the doctor and say: “it’s having an adverse effect”. There was a tablet (*pause*) (*sigh*)- there- there was a tablet that I was on years ago (*sigh*), oh, I can’t remember now what it was for and they- they took me off that one. As far as I’m aware, it didn’t have any adverse effect by coming off it.

**INT: But you’d like to know what it is that the tablet does that’s being stopped so that you know what to look out for?**

P03: Yes. Yeah. Yeah.

**INT: So, in terms of that decision-making about stopping a medication, would you wish to be involved in that decision-making?**

P03: (*sigh*) (*pause*) (*sigh*) It- it (*sigh*)- it’s really a question of if they told me, the doctor or- or whoever, told me that I could come off a tablet, I would take their word for it but I would see what effect that coming off it had as far as I was concerned and if it- I thought it had an adverse effect then I would go and see the doctor and say: “I’ve been taken off this tablet” or: “you took me off this tablet”, or whoever “and it’s having an adverse effect, can I go back on it?”.

**INT: And you’d like to then be able to be involved in the discussion?**

P03: Yes. Yes. Yeah.

**INT: So, the information that you would be seeking is around what it does and what you should look out for when it stops?**

P03: Yes. Yes.

**INT: So, in terms of the professional who you might have those conversations with, which professional at the surgery would you feel more comfortable in having those discussions with?**

P03: (*sigh*) No (*pause*), I- I- I don’t honestly know anybody down at my surgery because I so seldom ever go there so, I don’t really have a- an infinity with anybody down there (*sigh*). I mean, I know more people down there through the wife’s problems than I do through mine.

**INT: And would you see that kind of lack of relationship with any particular professional having an impact on decision-making?**

P03: It’s- it’s never bothered me, no. (*sigh*) I’ve taken the tablets and as far as I concerned those tablets are doing what they should have done. I mean, one of the tablets was- was for hand tremor and I did reach a stage where I couldn’t write. I could do hardly anything with the right hand, I couldn’t pick a cup of tea up with the right hand. Even now, I tend to pick a cup up with the left not the right because the hand- right hand, although the tablets that I’m on have done a lot for it, they haven’t cured it completely, and I still get a slight tremor in that hand, and I wouldn’t risk picking a cup of tea up and drinking it. I always pick it up with the left hand. Yeah. Yeah.

**INT: So, thinking again about discussions around stopping medication, when do you think those discussions should happen? Are there any triggers for that?**

P03: Well, I mean, as far as I’m concerned (*sigh*), if the doctor, or whatever, down at the surgery looked up and said to me: “I don’t think you should take this tablet anymore”, “I don’t think you need this tablet anymore”, I would stop it, but if I felt that that had an adverse effect on my take- not taking it, I would then go back to the doctor and say: “it’s creating this, that or the other, do you think I should go back on it?”.

**INT: And so, is underpinning that a need for the doctors to be reviewing your medication?**

P03: Yeah.

**INT: Yeah?**

P03: Yeah.

**INT: But you don’t know whether that happened.**

P03: I don’t know how often they review. I don’t even know whether they review.

**INT: So, is your expectation that they would be reviewing?**

P03: (*pause*) (*sigh*) I would have thought that it is some period in time, somebody would review the tablets you’re taking but I don’t know whether that’s a fact, and I don’t know whether it happens.

**INT: Do you think it should happen?**

P03: Well, I would have thought so because I would have thought that it’s some time (*sigh*)- you know, what the tablets were given you for (*sigh*) can get better, repair itself, or whatever. (*sigh*) I mean, I- I used to take one tablet, Primidone, and I took that three times a day and, I think, they took me off that but I haven’t been taken off any other tablet once I’ve been put on them and I just- I get the tablets and I automatically do a fortnight in these containers *(points to medication pot on table)* and when the week’s done, I fill the empty one up and start taking the other one and, at the end of the month, I go down and get a new load of tablets.

**INT: So, do you go down to the surgery to get them?**

P03: (*C03*) and I usually go down because (*C03*) doesn’t drive so, she can’t go down there on her own unless she catches the bus. So, we usually go down together, and I get my tablets and- well, we get my tablets and (*C03*)’s tablets at the same time.

**INT: So, is that from the pharmacy?**

P03: Yes.

**INT: Is that near the surgery then?**

P03: Yes, that’s right outside. You’ve got- that is the surgery and the door there goes into the pharmacy *(indicating with his hands)*. So, we just go in there and pick-up the tablets, or whatever.

**INT: And how often did you say you need to pick the tablets up?**

P03: Once a month. Yeah, they give me a month’s supply. Yeah.

**INT: And do you have to reorder your month’s supply or does that happen automatically?**

P03: I used to have to reorder but now (*pause*) my- my tablets happen automatically, don’t they, renew now? *(Asks question of his wife, C03)*

C03: No. No.

P03: Do you renew them?

C03: Yes (*laughter*), the wife does. You see.

P03: I don’t get involved in that you see so (*laughing*).

**INT: I can talk that through with (*C03*) what she needs to do.**

P03: Yes. Yeah. Yeah.

**INT: So, if we think about a medication’s been stopped, what do you think should happen after that? So, you’ve been told by your GP, your surgery, that this medication is going to be stopped, what should happen then?**

P03: Well, if they stopped a- a tablet, any of the tablets that I take, then I would know whether that’s had a- had an adverse effect (*sigh*). I think, it would probably take a week for that tablet to become fully out of my system because I’ve been taking it for so many years. So, I would give it a week and then if my hands were suddenly shaking or, you know, something else was happening that hadn’t happened before, then I would go back to the doctors and say: “I think coming off that tablet has had an adverse effect”.

**INT: So, if a medication was stopped would you like to be offered some sort of follow-up?**

P03: Well, I- I suppose if- if they took me off a medication and they did a follow-up in a week, or two weeks, that wouldn’t be a bad thing.

**INT: And what would that follow-up look like, do you think?**

P03: Well, it- I- I mean, I would have thought a follow-up would be for me to go down and see somebody and discuss the drugs and what I’ve come off and whether it’s had an adverse effect, and what that effect is, and whether or not I should either go back on or whether if I continue without it, whether that would get better. Because if you suddenly stop a drug, I can imagine that that would- whatever it was given you to do might come back, but it might tail away, if you see what I mean.

**INT: Yeah, I see what you mean.**

P03: So, I- I wouldn’t expect to go back on that drug immediately unless it had a really desperate effect.

**INT: So, would that follow-up need to be down at the surgery, or could you do that over the ‘phone? What do you think about a telephone consultation?**

P03: (*pause*) No, I think, it would need to be face-to-face with somebody. I don’t think a- a telephone conversation over the-, with that sort of thing would- no, it wouldn’t, it wouldn’t do for me, I don’t think, ‘cause (*sigh*) my mind’s not what it was, and I don’t think I could follow that on a- a telephone conversation as opposed to a face-to-face.

**INT: And so, if you were to go back for a face-to-face, would you want somebody with you to support you? Someone like (*C03*)?**

P03: Well, (*C03*)- (*C03*) would probably come down with me. Yeah. Yeah.

**INT: And so, in terms of those day-to-day processes that we started the conversation off with, and the photos that you took, if a medication was stopped, what impact would that have on your filled pots? How would that be managed?**

P03: I think, if something’s stopped, my biggest problem would be shaky hands because I’m on medication for this and it- it- whatever I’m taking for that, it works. It doesn’t cure it a hundred percent, and I’ve still got to be careful when I drink a- pick up a cup of coffee or a cup of tea, and I usually pick it up two-handed, but if I stopped whatever I’m taking for that shaky hand and it got worse, I would have to go back on it.

**INT: So, actually, that’s one of the medications you’d be much more concerned about stopping than any of the others?**

P03: Yes. Yes, than any of the others. Yeah, that has- that has an effect on the whole of your life. Yeah. Yeah.

**INT: So, it’s around the level of impact that it has on you as to which conditions that you’re being treated for have the biggest impact on your day-to-day life.**

P03: Yeah. Yeah. Yeah, I mean (*sigh*), I have a slight hand tremor now even with taking that medication but if I’m doing anything, and I get hold of anything, that’s fine. I get hold of that and I- I’ve got no problem. I drive, I get hold of a steering wheel, I’ve got absolutely no problem driving because my hands are steady and that’s all I need. So, if I had a steering wheel and they took me off all the tablets, I’d be alright (*laughter*).

**INT: So, thinking about a medication has been stopped, and let’s say it’s the day after you’ve just filled your two week’s worth of pots.**

P03: Yeah.

**INT: How would you manage that in terms of making sure that you don’t take that medication?**

P03: I would probably take that until I- I run out, in there (*indicates to kitchen where filled pots are stored)*, and then stop it. No matter what they told me (*laughter*).

**INT: That’s how you would manage it.**

P03: Or give me, if I got those already made-up, I would probably take them. Yeah.

**INT: And is that something that you would let the surgery know you were going to do, or would you just do it?**

P03: (*sigh*) Well, I don’t know, you’ve got me there (*laughter*).

**INT: But it is about the practical challenges, isn’t it?**

P03: Yes. Yes, it- it- it is. I mean, it’s what I can do with my life and what I can manage to do on my own, that would have the biggest impact, and if I came off the tablets, particularly the shaky hand ones, the rest of them, I- I could probably come off some of those and I could get by. But if I came off the shaky hands tablets and it had an effect, I would have to go back on them because I’ve reached a stage (*sigh*), I mean I was coming to the end of my working life when I came onto these tablets and it was beginning to affect me with my work because I was a carpenter so, I was measuring stuff and when you’re taking measurements and you’re scribbling things down, shaky hands don’t go with that, and it doesn’t go with a lot of the movements that you- you know, doing in your job, and that was really what triggered me into getting something done about it because they were getting so bad.

**INT: So, they are all the specific questions I had for you.**

P03: Right.

**INT: But is there anything else that you want to add around your medications, or stopping medications?**

P03: No, I don’t think so. I think, you’ve- I think, we’ve pretty much covered the whole database (*laughter*).

**INT: OK, I’m going to now switch the recording off.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

P03 Respondent

C03 Second respondent

- Interrupted sentence

***Audio* file: 34.16 minutes**