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

Transcript for interview

**P05**

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

***Note – interviewed in presence of his wife, who sometimes interjected and answered on his behalf. This has not been transcribed and reference only made to what she said when she was prompting P05 but not verbatim.***

**INT: So, we’re going to start with your photos. Thank you very much for taking the photographs. I’m just quickly going to number those because that just helps when we talk about them. Can I first of all just check, did you take those photos yourself?**

P05: Yeah.

**INT: Did you take them kind of spontaneously or did you plan what you were going to take your photos of?**

P05: No, I just suddenly got- spontaneous.

**INT: Just spontaneous, you thought: “oh, this is to do with medications, I’ll take a picture of it”.**

P05: Yeah.

**INT: So, we’re going to talk through each of the photos in turn, and I would just like you to tell me a little bit about the picture, what it says about your medication taking. So, if we start with photo number one, what does that tell us about your medication?**

P05: It’s quite a lot. It’s, it’s easier to do it that way.

**INT: So, by that way...**

P05: You can’t make any mistakes.

**INT: So, by that way meaning, it looks like a nomad system there.**

P05: It’s, it’s got my morning, noon and night. So, it’s-, I, I actually- yeah, like it’s easy to use.

*Prompted by wife that the chemist does it*.

**INT: So, it comes from the pharmacy already…**

P05: Made up.

**INT: Made up in the pots.**

P05: Yeah.

**INT: And that makes things easier for you.**

P05: Yeah.

**INT: So, tell me a bit a out photo number two, what does that say about your medications?**

P05: It’s-, I’ve just picked it up from the pharmacy.

**INT: So, you’ve got kind of a little stack of them, haven’t you?**

P05: Yeah, I’ve got a whole month’s. Yeah, I get a whole month’s lot in one go.

**INT: And that’s your stack having just picked them up from the pharmacy?**

P05: Yeah. Yeah.

**INT: Tell me a bit about photo number three then.**

P05: I was just preparing my breakfast. I, I do the same thing every day. I find life’s easier if I just do the same thing every day, you know.

**INT: Yeah. So, the medications that you take at breakfast are they more significant than the ones that you take at other times of the day?**

P05: Not really. No.

*Wife asks him if there are more pills in the morning.*

P05: Yeah.

*Wife prompts that she thinks there are more pills.*

**INT: So, you take the majority in the morning?**

P05: In the morning and there’s four at night.

**INT: Tell me a bit more about the other times of the day that you take them.**

P05: I, I don’t-, I just take ‘em- I, I just take ‘em morning and night.

**INT: Morning and night.**

P05: Not, not night, I take ‘em with tea-, after I’ve had my tea. Yeah.

**INT: So, both lots of medication are linked to a meal?**

P05: Yeah.

**INT: So, does having the meal prompt you that you need to have your medication?**

P05: Yeah, I think so. Yeah.

**INT: And you said that it makes it easier because you always do it the same every day.**

P05: Hmm.

**INT: How long have you been managing your medications like this roughly? Can you remember?**

*Wife clarifies whether the question is referring to having them in the Nomad.*

**INT: Well, just having them kind of morning and evening with breakfast and dinner.**

P05: Years.

**INT: Quite a long time.**

P05: Years.

**INT: So, something that you’re just quite used to doing?**

P05: Yeah.

**INT: Can you tell me about anything else that you have to do around managing your medication such as getting hold of the medications?**

P05: Just-, the only thing I’ve got to do is remember go and get it once a month.

**INT: Do you have to order them?**

P05: No, they, they do it. It’s done through the doctors. I just go there, and they’ve done it.

**INT: So, it’s a regular rolling prescription.**

P05: Yeah, and if they, if they had to change anything, it’s done through them. Yeah.

**INT: So, if something was to be changed, would they reissue the boxes, or would it just happen the next time the boxes…?**

P05: Hopefully, hopefully.

*Wife prompts that medication has been given separately and advised that it will then be in the next box.*

P05: Yeah.

**INT: And do you do all of this yourself or does your wife support you with any of it?**

P05: Yeah. She helps me find them when they drop out (*laughter*).

*Wife prompts that he does it all himself.*

P05: Yeah, and then the trouble is I shake when I’m taking them out and sometimes-. Heaven knows where they go.

**INT: So, anything else that you do regarding your medications?**

P05: No, just got to remember if we did go out somewhere, you’ve got to remember to take it. Put it in a bit of silver foil, and remember to take it, if you’re lucky (*laughter*). Yeah.

**INT: So, how do you feel about the number of medications that you’re taking? We talked earlier; you’re taking ten.**

P05: Well, I, I did talk to the doctor about it, get- try and get them down and he advised me against it, or she.

**INT: So, do you feel there’s too many?**

P05: Well, I’m completely used to it now but I, I (pause)- I can only say I did talk to them about it but he, or her, it was the lady, I think, and they said: “oh, no, let’s leave it, then we’ll leave it for now and we’ll talk about it later on”. So, I don’t think they’re keen on changing it.

**INT: How did that conversation happen?**

P05: I don’t, I don’t really know. I, I can’t-, I can’t-, oh, because we don’t very often see a doctor, you know.

**INT: So, was it maybe just as part of a ...**

P05: Conv- a conversation, I think. Yeah, I think, I was…

*Wife prompted him to think about whether it was the GP he spoke to or whether it was another doctor who had previously visited him.*

P05: GP, I, I think. Yeah, I think, we was having a, a jab, I’m not sure.

*Wife prompted that they have not seen the GP for ages.*

P05: There’s no point in ‘phoning the doctor is there? (*laughter*).

**INT: This is quite a while ago that you had that conversation.**

P05: Yeah. Yeah.

**INT: So, other than that conversation that you had where you raised the issue about potentially reducing your medications, are you aware of anytime when your medications have been reviewed?**

P05: Should be reviewed?

**INT: No, have they been reviewed?**

P05: Oh, they…

*Wife interjected reminding him he had been called in.*

P05: Yeah, what, once a year?

*Wife prompts that this was not often but had happened.*

**INT: Is that the GP surgery?**

P05: Yeah. Yeah, it was a long time ago.

**INT: So, you’ve obviously at some point had a conversation and reviewed your medications, can you tell me a bit about that? Who was that with?**

P05: (*sigh*)

**INT: I don’t need to know the name of the person, sorry, but the professional group.**

P05: It would be the doctor’s surgery.

**INT: It was up at the surgery. Was it a doctor?**

P05: Yeah *(wife speaks as well)* it was a doctor. I think, he was checking (pause) I think, he was checking the (pause) I think, he was checking the blood pressure. (*undecipherable words*). I think, I can’t remember now. Yeah, it was definitely a bloke, it wasn’t a lady.

**INT: And did you talk through all of your medications?**

P05: No. No, just-, I, I, I must… (*wife interjected).*

**INT: And so, as a result of that review when he looked at your medications, took your blood pressure, was anything changed in your medications that you can remember?**

P05: No. No. They have changed something since, didn’t they? They’ve changed the little tablet but that was because I went to-, was it when I went to the fall’s clinic? Did they change it then? I used to have a lot of letters there. They added, they added-, oh, no-, yeah, yeah, it was. Oh, it’s so…

**INT: Take your time.**

P05: And they took some bloods and then the doctor wrote to me and said they’re going to add a little-, another tablet because something was deficient.

*Wife prompts that it was folic acid.*

P05: I think so. Yeah.

**INT: So, they added that in?**

P05: Yeah.

**INT: Have you ever had a medication stopped in the past?**

P05: No.

**INT: Just more added in.**

P05: Yeah. I-, there, there-, well, years ago, there was one that dried my mouth up but I can’t remember what it was. That was donkey’s years ago. But I had-, that was a weeing one, wasn’t it?

**INT: So, it obviously hasn’t happened in your case thus far but sometimes it may be decided that a medication isn’t needed anymore. What do you think about the idea of stopping medications?**

P05: I don’t mind. I don’t, no.

**INT: Would you see that as a usual part of managing a condition or something that’s quite out of the ordinary?**

P05: Well, they would only stop it if it wasn’t necessary. I mean, logically you’d think you’d come off ‘em all, wouldn’t you, but you can’t.

**INT: So, you’d be quite happy to come off them all from the conversation we’ve had?**

P05: If they-, if they said, yeah. I’m no good at making decisions so.

**INT: So, if we think about decisions about stopping medication, what might make you want to stop a medication?**

P05: I can’t think of anything.

**INT: Of the medications that you’re on now, are there any medications that you would be more concerned about stopping?**

P05: Umm, the only thing I can say is I, I wish that they could have made the one that the Professor gave us, I wish they-, I could have ca-, I think, I still take it but it, it don’t work like it used to, do it?

*Wife asks if he means the dementia drug Memantine.*

P05: Yeah.

**INT: So, initially it had...**

P05: Yeah, I seem, seem to remember.

**INT: So, in thinking about medications that you would be happier to stop and ones that you’d be less happy to stop, where does that one sit?**

P05: I can’t, I can’t think of one I really would think would, no, I can’t think of one.

**INT: So, with the dementia drug, would you be happy to stop it or less happy to stop it given the impact it has?**

P05: Oh, I’d be less happy, but I don’t, I don’t think it’s working now like it did. Yeah, but (pause) er.

**INT: So, if somebody suggested that that medication was stopped, what would you concerns be?**

P05: It’ll get worse quicker. I-, I’ve, I’ve got a friend in Belgium, he’s- six month and he-, I’m lucky, it’s slow. Yeah, everybody says, do you know: “oh, you’re lucky it’s slow”.

**INT: So, I don’t think we’ve identified a tablet that had been stopped apart from the one that you said was stopped because of the dry mouth.**

P05: Dry mouth, that was in there.

**INT: So, that was stopped because you were having side-effects?**

P05: Yeah.

**INT: So, if the professionals were thinking: “oh, it might be quite useful to stop a medication”, how do you think that’s best approached with you? How do you think that decision should be made?**

P05: Well, at my age and-, I can only take their advice.

**INT: Would you want to be involved in that decision-making?**

P05: Yes. Yeah. Well, I’m, I’m not saying I’d go against it, but um.

*Wife prompts about wanting to know the reasons.*

P05: Yeah.

**INT: So, understanding the reasons. Would you have any specific questions that you might want answered other than, you know: “why are you stopping it?”?**

P05: No.

**INT: And is there any particular professional that you would think it’s more appropriate to be having that conversation with?**

P05: Cor, I wish I could be that lady.

**INT: Was she a consultant at the hospital?**

P05: Yeah.

*Wife prompts with name of hospital and role.*

**INT: So, she was a consultant in dementia care?**

P05: Yeah. The trouble is then she left and went to (*hospital*), didn’t she?

**INT: Tell me a bit about what it was that gave you that trust in her?**

P05: Umm, I don’t know. She, she, she just understood. I don’t think a lot of them do understand.

**INT: So, understood the dementia?**

P05: Yeah.

**INT: So, she was a dementia specialist, how would you feel about her reviewing all of your medications including things for non-dementia?**

P05: Oh, that would be OK. Yeah, because they’d have to liaise with the doctor, I suppose. Well, they tell the doctor, don’t they? Yeah.

**INT: So, there needs to be some sort of liaison.**

P05: Yeah, I, I, I don’t know. I-, but I mean-, but the doctor down the Fall’s clinic, he’s quite nice, isn’t he? He’s, he’s, he’s understanding. He’s quite a nice fella.

*Wife prompted that the Fall’s doctor had not been able to advise him on something he had asked as it was not his area.*

P05: Yeah, that’s right. That’s right. I think, it was something to do with the shaking.

**INT: So, just as an understanding, how many different professionals do you have involved in your care? Obviously, the falls clinic, the dementia clinic.**

P05: I’ve-, when that lady-, we went to the dementia clinic, they was, they was brilliant, and then the next thing we know is we get a, a visit and it’s all going to stop and everythings gotta be done by your doctor, by your doctor. And it’s a complete waste of time. Really, because doctors won’t even see you. So, if, if I was in a crisis, I’d, I’d-, I’m, I’m lucky because I can ‘phone *(local community dementia service*) that…

*Wife prompts about the clinic doctor.*

P05: Yeah. The lady doctor down the surgery is good.

**INT: So, you’ve got that clinic, you’re no longer under the dementia services, that’s covered by your GP. Have you got any other consultants involved?**

P05: No.

**INT: Yeah. So, you were saying it was a waste of time with the GP, explain a little bit more why you find that such a waste of time. You’ve obviously mentioned that access is difficult.**

P05: Well, if you ‘phone up the GP, how do you tell, how do you tell somebody behind the desk what’s-, what’s wrong? And if you do that, it takes months to get, to get an appointment.

**INT: So, actually, it’s primarily around access?**

P05: Yeah.

**INT: When you do get to see a GP, how do you find that in terms of their management of all of the different conditions?**

P05: The last time I saw a lady, she was pretty good, but that was (*name*)’s friend.

*Wife prompts that she is their doctor*.

P05: She’s-, yeah, she, she was good, she was good. She didn’t rush you in and out or anything, but that’s her recommending me to the falls clinic, but that’s the only time I’ve ever seen her.

**INT: So, you mentioned not being rushed.**

RESP: Yeah.

**INT: So, time is important?**

P05: Yeah, it did-, seems like you go in there and they’re getting you out. Yeah.

**INT: Do you think that’s become more important since you’ve developed memory issues?**

P05: Nobody down there really never asked me about anything about memory issues. I don’t think they’d know if I did.

**INT: Do you think they make any adaptions for you when you go to see them because of your memory issues?**

P05: No, I’m not, to be honest. No.

**INT: (Directed to wife) So, do you usually go with (***P05***)?**

*Wife responded that she did not always go with him.*

*She prompted P05 about a code that a previous doctor had given them so P05 could get to see him.*

P05: (*name of doctor*), he was brilliant. He left. Yeah. Yeah.

**INT: So, say the GP had invited you back, like they did however many years ago, to review your medication.**

P05: Yeah.

**INT: Would you want your wife to be with you for that discussion or would you be happy to do that on your own?**

P05: Well, I think, we’d do it better together, wouldn’t we? Yeah.

*Wife prompted that he wouldn’t remember what had been said.*

**INT: So, in your past experience, have you ever had any experience of what we would call shared decision-making so, being involved on a kind of even level in making a decision about treatment or medication? Have you had any experience of that?**

P05: No. The only time that anything like that was really, was when we went to the clin-, we, we done the research thing. They, they was brilliant. Yeah. No. No. I’d say really now we just hang on to (*local community dementia service*) but they’re, they’re not professionals but at-, at least there’s a, a nurse there who you can ask, and she would probably get to see the doctor.

**INT: Tell me a bit about the (*local community dementia service*) service.**

P05: Well, I, we go-, we, we, we go once, once a week.

*Wife prompts that he goes on his own.*

P05: I do, but (*wife*) comes down every, once a month.

*Wife prompts that this is for the carers meeting.*

P05: Yeah, and we don’t really-, they like play games that can use our memory and that, and you’re all the same, you know, you’re not..

*Wife prompts that some are worse.*

P05: Some, oh, yeah, some of them are a lot worse.

**INT: And that’s run by professionals, you mentioned, and a nurse.**

P05: Yeah. Yeah. Yeah, I, I, I, I don’t, I don’t, I don’t-, yeah, I know the nurse, she works at (hospice), and she, she comes in there so-, but I, I think-, well, the-, well see, the lady who’s running it now, well, who’s organising it, she’s an ex-, she’s left teaching at school and she’s come there and she’s had to go and do some courses I, I think, and like she, she’s taken it over now. So, I, I don’t think it’s like a, a…

*(Wife interjects that they aren’t professionals).*

**INT: But you do have access to a nurse if you had some specific problems.**

P05: I’ve got a ‘phone number, I could ‘phone the nurse on if, if, if I-, or I could ‘phone one of the helpers. Yeah.

**INT: So, let’s imagine that the GP’s invited you in, reviewed your medication and made the decision to stop a medication. What would you…**

P05: I’d want to know why.

**INT: Yeah, and then you’ve agreed with them, and you think: “OK, I’m going to go ahead and stop it”.**

P05: Yeah.

**INT: What would you want to happen next? So, what would…**

P05: I’d want, want the-, what? You mean-, I’d want them to keep an eye on it because well, obviously it’s coming off of the drug, isn’t it?

**INT: So, what would you want that follow-up to look like?**

*Wife answered.*

**INT: So, what are your views on that?**

P05: Well, would they call you in? I, I-, do…

**INT: What do you think should happen? Let’s not think about what would happen, let’s think about what you would want to happen.**

P05: I, I think, if we say I can ring them, they should keep con- in contact with me.

**INT: And how would that contact need to be?**

P05: I, I, I mean, I, I wouldn’t mind going to the surgery, or the hospital, wherever it is.

**INT: Would it need to be face-to-face, or would you be happy with a ‘phone call or an e-mail?**

P05: It all depends to what degree it was.

**INT: And what information would you want to come away with after the medication’s been stopped?**

P05: Well, I certainly wouldn’t, wouldn’t want to think it was going to get worse quicker, but it’s quite frightening, you know. No matter how tough you are, you-, when you stop and think about it, you know, you could be walking somewhere and you suddenly don’t know where you are. It’s not natural.

**INT: So, I think, what you’re saying is the follow-up you would need would depend on which medications it was that they were stopping. So, some of the medications you would be more concerned about stopping.**

P05: Yeah.

**INT: Of the medications you’ve got on your current list, which ones would you say you were less concerned about stopping?**

P05: Probably just the er, the black one.

**INT: Is that the Vitamin one?**

P05: Vitamin one. Probably. I would just see what happened. Yeah. I assume the others are necessary.

**INT: So, do you know what you are taking your medications for?**

P05: I haven’t got a clue anymore.

**INT: And we’ve already established that if a medication was going to be stopped then it would either get added in as an extra medication from the pharmacy until such a point as it can get into your Dossett boxes.**

P05: Yeah.

**INT: How does that work? Does that create any problems having something separate to take on top of having your box?**

P05: It would do, I suspect. It’s just a matter of remembering to do it.

**INT: So, there’s a memory issue there.**

P05: Yeah.

**INT: Is that where (*wife*) might prompt and say you’ve got an extra one to take?**

*Wife prompts that she might.*

**INT: So, if you were to stop a medication, would you think that (*wife*) might want any support following that as part of that follow-up? Would you see (*wife*) being involved at all?**

P05: Yeah. Yeah.

**INT: So, in what way would (*wife*) be involved?**

P05: Well, I lean on her all the time so. I’m a pain in the backside (*laughter*).

**INT: So, we’ve established that you’d want (*wife*) there at the time that that decision was made so that then she was fully informed.**

P05: Yeah.

**INT: So, I think, that’s all the general questions we’ve got around the medications. Is there anything else that you want to add about stopping medications? Your kind of views generally about stopping medications?**

P05: Not really. No. It’s a fact of life.

**INT: So, you see them as just necessary.**

P05: Be nice not to have to take ‘em.

**INT: But equally, you said it would be worrying if one was stopped.**

P05: Yeah. Yeah. I haven’t been much help really, have I (*laughing*)?

**INT: You definitely have. Let me just stop the recorder.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

P05 Respondent

***Audio* file: 34.04 minutes**