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

Transcript for interview

**P01**

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

**INT: So, we’re going to start with your pictures.**

P01: Hmm.

**INT: Just kind of talk through the pictures that you kindly took for us and what they indicate about how you manage medications on a day-by-day basis.**

P01: Right.

**INT: So, if we can start with this one. So, can you tell me a bit about the picture.**

P01: Alexa is--- is just a reminder.

**INT: It’s a reminder.**

P01: Hmm.

**INT: So, how do you use Alexa as a reminder?**

P01: Normally, I’m shouting at her, telling her to: “shut up” or: “do as I ask” but…

C01: I--- I recorded a reminder on it to play at ten o’clock in the evening so that the evening tablet doesn’t get missed because that was the one that was getting missed.

**INT: So, it gives you that regular reminder that you need to take your medication.**

P01: Yeah. Yeah. Yeah, she’s pretty good at doing that.

**INT: So, if we move on to the next picture. That looks like breakfast time.**

P01: It is, and I just associate these objects with medicines with er, with having my breakfast and er, and that’s the correlation that takes place between that bowl and that (*laughter*)[points to medicines in photo 2].

**INT: Do you take more of your medications in the morning than at other times of the day?**

P01: Oh, yeah. Yeah. Yeah. Yeah, that’s, that’s the majority of all, early mornings.

**INT: So, that’s kind of that association.**

P01: Yeah. Yeah. Yeah. So, that’s why we need her in the evening [points to Alexa].

**INT: How many medications do you take in the evening usually?**

P01: Just the one.

**INT: Just the one.**

P01: Just one.

**INT: And in terms of this next picture [picture 3], can you tell me a bit about that one?**

P01: Just to let me remember (*laughing*) where they are (*laughing*).

**INT: Oh, sorry, I put it upside down.**

C01: No, it’s alright.

P01: And the dates. Yeah.

C01: It’s the evening pot because that’s the one he needs most, well, any reminders to take. So, that’s the one I’m more involved in than breakfast.

P01: Yeah, breakfasts I can manage myself because that’s now a routine but that come the end of the day is pretty meaningless to me.

**INT: So, how many times a day do you take medication?**

P01: Twice.

**INT: Twice. So, just morning and evening.**

P01: Yeah. Yeah, just morning and evening.

**INT: So, the bulk of them are in the morning and then just the one at night.**

P01: Yeah.

**INT: And what about this last picture here [picture 4]?**

P01: I’ve no idea.

C01: Well, look at it.

P01: (*pause*) Filling up my little pot.

**INT: OK, and how is that done?**

P01: With my fingers (*laughing*).

**INT: So, you fill that how often?**

P01: Well, I do it once a week. Yeah (*pause*).

**INT: How about how you get the medications? How do you get your medications so they’re here and ready to go in the pot?**

P01: I walk up to the chemist.

C01: But what do you do before that?

P01: Well, I have to ask the doctors to present the requirement for medication.

C01: How do you do that though?

P01: What do you mean? How do I do it? I do it online.

**INT: So, you do it online?**

P01: Oh, yeah. Yeah.

**INT: So, in terms of managing medications on a daily basis, there’s a few things you’ve mentioned that kind of help you to do that. So, you’ve got Alexa which is there for your reminder.**

P01: Oh, yeah. Yeah.

**INT: You’ve got your wife who (*Alexa talking in the background*).**

C01: Alexa, be quiet.

P01: That’s what really annoys me (laughter).

**INT: Sorry, that was my fault (*laughter*). So, you’ve got your reminder, you’ve got your wife who is helping you as well with your evening medications.**

P01: Uh huh.

**INT: You’ve got your online system for doing your ordering.**

P01: Yeah.

**INT: Is there anything else that helps you with managing your medications on a daily basis?**

P01: Nothing I can think of immediately. Do you--- is there anything else I do?

C02: (*pause*) No.

P01: We’ve got that little clock thing over there [points to clock which displays time, day and date on side near kitchen/diner table].

**INT: And what does that do?**

P01: Remind me of what day it is and what time it is (*laughing*).

**INT: So, in that sense, reminds you about which pot you’re taking your medication from.**

P01: Yeah. Yeah. Yeah. I do get confused about days now. What day it is and things like that.

**INT: So, that just helps.**

P01: Oh, yeah.

**INT: To kind of orientate you to where you are in the week.**

P01: Hmm, and quite often I’d ask the time and when are we doing things and…

C01: Yeah, I mean as far as tablets go.

P01: Yeah.

C01: You ask more for the day than anything else because the pot is labelled out Sunday to Saturday and (P01: (*coughs*)) unless you start on Sunday and go through to Saturday, the empty pot might be in the wrong place if that makes sense.

**INT: Yeah. So, that helps you kind of associate that and check where you are with the pots.**

P01: Oh, yeah. Yeah. Yeah.

**INT: Do you face any challenges with managing your medication?**

P01: Well, I find it quite boring if that’s included as a challenge, but I do find the whole (*pause*) discipline that’s required to take it annoying.

**INT: Annoying because of?**

P01: I have to remember it (*laughter*).

**INT: Oh, yeah.**

P01: And I just find it annoying.

**INT: OK.**

P01: One, that it, it annoys me because I can’t remember to do it and I find that quite frustrating, the fact that I’ve forgotten or I’m being reminded by (*name of wife*) to do things, and that I find, well, not constraining but I do find it difficult because I think: “well, by then she…”--- and then I think: “oh, why are you telling me that for?”, you know: “I’m not particularly interested in that. I’m not interested in any of these things (*laughter*) so, why do you think I’m going to take any notice of it?”. Alright, they may well--- well, do they keep me alive? I don’t know. If I stop taking them, would I die? I very much doubt it, but it just seems like it’s interfering with whatever I’m doing at that particular moment in time that I’m being reminded to take a tablet (*word ‘tablet’ stressed by being said slowly and with a sigh seeming to indicate frustration*) and you think: “well, is that tablet actually doing anything?”. I mean, how do you prove it, disprove it? If I stop taking them, would I drop down dead immediately? I very much doubt it.

**INT: So, the study’s very much about stopping or reducing medication. So, how do you think if you were asked to stop one or more of the medications it might impact on this day-to-day routine that we’ve had?**

P01: I wouldn’t give a fig myself but then, and then my, I dare say my wife would have a totally different point of view because I just think: “oh…”, you know: “I don’t know if it’s actually beneficial to me or if it’s helping me or keeping me alive. If I stop taking it…”, you know: “what would happen?”. Quite often, I’m tempted to stop taking it just to see what does happen.

**INT: And is that all of your medications or just one or two particular ones?**

P01: Oh, yes. Well--- yeah, yeah, I’m getting a bit bored with it now, to be quite honest, because I’m getting bored with the repetition of it and it sort of (*pause*), I don’t know, sus, suspends my life in some ways. You think (*sigh*) that somebody’s giving you something that’s supposedly going to help you, but I have no way of being able to verify what they’re doing and what they’re saying to me, and, and, and that loss of having some influence over (*sigh*), over your life is, is, is quite frustrating.

**INT: So, if we think more about this idea that sometimes health professionals might think that something could be stopped, or could be reduced, perhaps because they think that it might not be having any benefits anymore or perhaps…**

P01: But how do you prove it? How do you prove there’s benefit to it?

**INT: OK. So, I suppose, sometimes that’s around benefits in terms of ...**

P01: Saving money (*laughing*).

**INT: Side-effects versus no side-effects against symptoms that you might be experiencing (**P01: (*coughing*)**). But if a professional did suggest to you that one or more of your medications could be stopped or reduced, what would you think about that?**

P01: Why? I want evidence from him to, or her, to say: “this is the reason why we’re…”, you know: “cancelling this medication”. I mean, they’re quite random. I mean, I’ve had medication cancelled but not, I’ve, I’ve got no idea why it was cancelled. It was never explained to me as to what, what the purpose of taking the drug in the first place was and then replacing it with something else. You know, there, there, there doesn’t seem to be any commonality between the, what goes on in their head and what goes on in my head.

**INT: So, a sense there of wanting to be involved with that decision-making?**

P01: Well, I’d like to think so considering it’s my body (*laughing*).

**INT: So, what information might you think would be useful?**

P01: Well, why am I being given them and what exactly do they do and what exactly is the purpose of them (*coughs*) and how do I define that benefit to myself in terms of my overall health?

**INT: So, thinking about the healthcare professionals that you might have that discussion with.**

P01: Well, I never see very many, to be quite honest. They, they, have you tried to see a doctor (*coughs*)?

**INT: Yeah.**

P01: I may as well fly to the moon. I mean if you said: “oh, well, why are you giving me this medication?”, “I want to know why and what’s the purpose of it and does it actually do anything?”. The only one I have a most oddly small amount of faith in is Donepezil that I take and, I mean, the other stuff they’re saying about, oh, you know: “stomach explosions” and, and, and you’re thinking: “what?”, you know, but those all seem, I, I, I dare say they’re a necessary part of whatever the drug is that they’re taking to but (*pause*), no.

**INT: So, I’m sensing that you’re feeling like you haven’t got enough information about all of the medication that you’re taking.**

P01: Hmm. Hmm, and for what purpose?

**INT: Yeah. So, putting aside the sort of difficulties with having those discussions with healthcare professionals.**

P01: Yeah.

**INT: Which I completely understand, what would you think would be the best situation in which to have that sort of discussion about medication? When, for example, would be a good time?**

P01: Any old time (*laughing*). I’m not worried about time. I’ve got plenty of time to waste.

**INT: So, in terms of your appointments with doctors, are there any opportunities there for you to have such discussions?**

P01: No (*laughing*). You normally don’t get to see a doctor anyway. It’s normally a, a, a nurse or something. You know, a clinical something or other but you don’t get to speak to a doctor about the condition. The last time I spoke to a doctor must have been two years ago and everything else seems to be palmed off.

**INT: So, what about these other healthcare professionals? Would you feel able to have a discussion with them?**

P01: Not really because they generally don’t have that attitude, or necessary attributes, to be able to answer your questions.

**INT: So, there’s something about the type of healthcare professional that is most appropriate to have the discussion.**

P01: Yeah. I mean, I, I mean, I have asked people previously. If I’ve gone in to have an injection or something like that and I say: “what’s this being done for?”, “I don’t know, I just take injections” was how it came over to me, not the fact as why’s it being done or what’s the purpose of it?

**INT: So, you’ve got a missing bit of information there, haven’t you?**

P01: Yeah, and I quite like storing information as to, you know, why I am being asked to do things but, well, I, I seem a little blind in that respect as to actually finding somebody who says: “well, you’re going to take this because this will do that and that will stop this from happening” blah blah blah. You don’t get a very (*pause*) particularly clear vision as, as, as to what’s happening to you.

**INT: So, if you were to be able to have that conversation about stopping or reducing a medication, what would encourage you to actually go ahead and stop or reduce it?**

P01: Proof. They give me proof as to why I should stop taking it.

**INT: And what would that proof look like?**

P01: (*pause*) (*laughing*) Well, I, I don’t know how you describe that in, in, in one word. I mean, the proof would be that they show me in some manner as to how that would be of benefit to me.

**INT: So, if you decided to stop or reduce the medication, what would you be looking for after that in terms of support from the professional who’s advised you about stopping it? Would you be looking for support?**

P01: No, I, I’d be looking as to why he’s doing it. I mean, I, I wouldn’t necessarily have an immediate objection to it because I know some of the, the medication I take is, I, I don’t know quite why I’m taking it and, and that’s my biggest annoyance is I don’t understand.

**INT: So, some medications you’d be happier to stop than others?**

P01: Yes. I mean, be good, but I don’t know if stopping those will affect anything else so, that’s the bit that’s sort of like, it’s a bit tenuous as to how you make that decision.

**INT: So, that probably answers my next question about what would be the reasons for not wanting to stop or reduce the medications.**

P01: Hmm.

**INT: So, it’s understanding that broader, how it kind of fits in.**

P01: Yeah. Yeah.

**INT: So, in terms of what your healthcare professional could do to assist you with understanding that.**

P01: Well, I’d like somebody to sit in front of me and say: “you take this for that and this is what it does”, “and this is how it works”, “and these maybe are some of, some of the side-effects that come from it”, “these are the positive things that come out of it” but you don’t ever have that conversation. They don’t say: “well, if you take this, this is what, this is what it does”, “if, if, if you don’t take it, then this is, these are the, the consequences of you not taking it” but nobody gives you that explanation. So, you go online and you look at things and you think: “well, I don’t think I understand anything (*word stressed by tone*) about what it actually is anymore (*laughing*) than I did before” because there’s been no interaction there with, with, with a fellow human being. So, I don’t know if any of those tablets are actually doing anything for me.

**INT: So, what you’re describing to me leads me to ask you how would you feel about having a medication review? So, when all of your medications are looked at by one healthcare professional.**

P01: I would think that would be a very, very sensible, so long as (*laughing*) they have the ability to be able to explain why I’m taking a particular thing. I mean, I can read what it says on the front but it doesn’t really help that much (*laughing*).

**INT: Would you consider other professionals than just doctors to do that?**

P01: If somebody knows what they’re talking about, I don’t care who it is, but it has to be somebody that, I, I would say: “well, why am I taking this?”, “what does it do exactly?” and: “will I have to take it for ever?”, “if I stopped it, would it make any difference?” (*pause*) and, and those would be the things that I’d like to know. There you go (*laughing*).

**INT: So, if we were thinking about having a discussion about stopping or reducing medication, how do you think that best takes place?**

P01: Well, someone comes and talks to me (*laughing*).

**INT: So, face-to-face?**

P01: Yeah, I would prefer face-to-face. Yeah. I don’t know, I don’t think I’d be particularly satisfied by a ‘phone call for something like that.

**INT: So, I’m guessing from our discussion so far that you haven’t ever had a discussion with a professional about stopping or reducing medication?**

P01: Never. I mean, they tell me while that what they’re going to give me but they don’t tell me quite what those things that they’re giving me are going to do. They don’t necessarily explain to any great extent why I’m taking them and I find it quite frustrating because I’m feeling like I’m being treated as a, a, a child in some respects and you say: “well, you take these little sweeties” and whatever happens next is what happens next.

**INT: So, you say that it makes you kind of feel like you’re being treated as a child. How could that be changed?**

P01: By not treating me as a child (*laughter*). By explaining in most probably a little bit more depth as to why I’m taking that medication, what purpose does it have. If I stop taking it, what would be the consequences of stop taking it?

**INT: So, a little bit more detail about your medication.**

P01: Yeah. Yeah. Yeah.

**INT: So, if somebody was to talk to you about stopping or reducing medication how might you like that to look, that discussion? So, we’ve talked about it being face-to-face.**

P01: Hmm.

**INT: Anything around when that might happen or how it should be raised with you?**

P01: (*laughing*) Perhaps someone can ring me up and say (*laughing*): “do you want to come along and then we’ll tell you more about your medication?” because I feel, I, I do feel as though sort of my will is displaced by somebody else’s (*pause*) thoughts in terms of: “well, you’re going to have to have this” and I’m not, not, not, am I rebellious? I suppose in some way, but I do find it quite annoying that it’s never been explained to me as to what this medication does apart from reading what it says on the side.

**INT: Has anyone ever explained to you about what that medication does in association with the other medications?**

P01: No, nobody ever. I wouldn’t know if one thing interfered with another thing. I mean, no, I suppose, that’s why some of the medications I have been previously prescribed had been withdrawn because eventually somebody said: “oh, well, you can’t have that one because that will make most probably interfere with this” because I was on statins and then the statins just miraculously vanished and never appeared on the list again but noone said: “oh, you’re not going to have these” because they were saying: “well, supposedly a high risk of a heart attack” but, but they just stopped, they just vanished.

**INT: And there was no discussion?**

P01: Yeah, there was no discussion, and I couldn’t be ar\*\*d to ring him up to be quite honest.

**INT: So, that’s obviously made you feel like you’re not part of the decision-making.**

P01: Very much so.

**INT: That’s what’s coming across.**

P01: Yeah. Yeah, but I imagine everybody else has exactly the same (*dog barking*) situation, you know, the same (*pause*) inability to be able to speak to somebody to say: “well, why did you suddenly stop doing that?” because you ring them and you just sit there on the telephone for half-hour, if not more, and still don’t get sufficient answer.

**INT: Have you been able to pick that up at a kind of subsequent appointment for something else?**

P01: Well, normally, I’ve forgotten by then (*laughter*).

**INT: So, it just disappears off ...?**

P01: Oh, yeah, yeah, it will do, you know, someone would call me in, or they’d say if I do mention it that: “I don’t know anything about that”.

**INT: So, very difficult to get information.**

P01: Oh, oh, yeah, yeah. I mean, yeah, if you go for a blood test and you ask the girl who’s, or the man, whoever is taking your blood test: “oh, I’ve also questioned this” or whatever and they go: “oh, all I do is take blood”.

**INT: So, actually getting answers is quite difficult from what you’re saying?**

P01: Yes, very difficult (*laughter*).

**INT: So, if you were able to have a discussion with a healthcare professional about the medication, what might help you to feel like you’re part of a shared decision-making process?**

P01: I, I, if it was explained to me exactly why I was taking them, I would most probably think: “well, yes, it’s most probably a better idea to keep taking them than not taking them” but nobody really gives you any insight into why (*word stressed by tone*) you’re taking them, and that’s the most frustrating part.

**INT: So, not just the initial prescribing of them but if it was to be stopped or reduced, the same level of information.**

P01: Oh, yeah, yeah. Yeah. I think, that’s (*laughing*) quite relevant. It’s not irrelevant, I mean, but things just suddenly disappear, and you think: “well, I don’t know what happened to that”.

**INT: But to be involved in that decision is important to you?**

P01: Yes. Oh, yeah. Yeah, it would be quite nice (*laughter*). Well, I, I mean, polite as well, to be honest.

**INT: Yeah. So, let’s put ourselves in a situation where you’ve managed to have a conversation with a healthcare professional. They’re suggesting that you stop one of your medications. They’ve explained why and you’re kind of in agreement that that’s something you’d like to take forward.**

P01: Yeah.

**INT: What support would you like after stopping that medication to make sure that everything is OK?**

P01: Well, maybe someone to just check with me that, or my wife, or whoever, to, to see if they see it, if they see any changes. I mean, I won’t necessarily recognise the change but I daresay (*name of wife*) would recognise a change.

**INT: So, it’s important to you for (*name of wife*) to be involved in these discussions as well?**

P01: To a certain extent, yes, because ultimately, she’s the person who reminds me to take the medication, reminds me to eat, you know, so, it’s quite useful (*laughing*). Most probably not talking to me but to (*name of wife*).

**INT: So, perhaps both of you?**

P01: Hmm.

**INT: Together.**

P01: Yeah.

**INT: So, that you’re involved in the decision-making. But (*name of wife*) hears what’s been discussed.**

P01: Yeah. I mean, sitting here now, I can’t remember what you said two minutes ago. It’s, it’s nothing. It’s just, there’s nothing even there that would give me a reminder as to what we’ve spoken about and that’s the bit I most probably hate the most, that I don’t have that memory recall anymore, and I find that particularly frustrating.

**INT: Really difficult.**

P01: Hmm.

**INT: Yeah. So, having (*name of wife*) there would help.**

P01: As a prompter. Yeah (*laughter*), the prompt (*coughs*).

**INT: So, in terms of that kind of support, you would like to have (*name of wife*) there so that she’s aware of what’s being decided.**

P01: Yeah.

**INT: And also some sort of follow-up support.**

P01: Yeah, I mean, she, she’ll remember it. I won’t remember it and people talk to me like they think I’m going to remember things and guess what? I don’t remember them and so, you know, I don’t know why. I say: “oh, I’ve got Alzheimer’s”. “Oh, that’s alright then” and you have this conversation. I, I, and it just disappears. It’s not there anymore.

**INT: So, if (*name of wife*) wasn’t able to be there with you, what else could the healthcare professional do to help you with that?**

P01: Write it down for me or put it in a letter or send me an e-mail. Things like that would be useful.

**INT: So, some sort of written outline of what you’ve discussed and what you’ve agreed then?**

P01: Hmm. I do find that, you know (*pause*), very frustrating.

**INT: Yes, I can hear that, and I can appreciate that as well. So, anything else that would need to be in place? So, some sort of written confirmation or (*name of wife*) being present. Some sort of follow-up. Let’s just talk a little bit more about what that follow-up might look like. How do you feel that needs to take place? Face-to-face, telephone?**

P01: I don’t really care so long as there’s someone competent that can answer any questions I want to ask. I mean, is there (*pause*) no, I, the, the, the delivery method is irrelevant so long as it’s somebody that gives me a, a qualified reason as to why these things happen or don’t happen then I’ll, I, I would be happy with that.

**INT: OK. That’s been really helpful. That’s the end of my questions.**

P01: Hmm. Hmm.

**INT: Is there anything else that you’d like to add? Anything else relating to your medication that you’d like to add?**

P01: Not particularly. No, not that I can think of immediately.

**INT: No glaring things about managing your medication that comes to mind?**

P01: No. No, I mean, as I say, (*name of wife*) reminds me or I’ve got Alexa, and I’ve got my little thing up there [reference to clock]. I, I, I do find it all extraordinarily annoying (*laughter*).

**INT: Yeah.**

P01: But then--- then--- so, I mean, I--- but I still get back to the thing, if I don’t take it, what would happen to me? I’m getting a bit bored with it all now. I am truly bored of feeling like this because it’s not what I was and now you have to cope with the fact that you have to sort of ask people about five times to remind me of somebody’s birthday or things like that. So, I do find it quite strenuous. I daresay you see, you know, people that are worse and people that are not that worse.

**INT: But these things impact everybody as individuals, don’t they?**

P01: Yeah. Oh, yeah. Yeah. Yeah.

**INT: So, if you haven’t got anything else about medication, then let’s just stop the recorder.**

P01: Uh huh.

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

P01 Respondent  
C01 Second respondent

***Audio* file: 32.10 minutes**