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

Transcript for interview

**P07**

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

**INT: So, let’s start off with your photos. I’m going to give you the first page and I’ve numbered them number one and number two. Did you take those yourself or did your niece take them?**

P07: We did it together, didn’t we really. *(Niece agrees they did it together.)*

**INT: So, you said what you wanted the photos taken of and you planned them, did you?**

P07: Yes.

**INT: So, starting with the page with the two pictures on it and let’s look at photo number one at the top, can you just tell me a bit about that photo? What does it say about how you manage your medications?**

P07: Yeah. Yes, I’m not allowed to-, one of those.

**INT: So, can we just talk about photo number one? If I remember rightly, that’s a clock, isn’t it?**

P07: Yes.

**INT: So, how does that help you with how you manage your medications?**

P07: The carers come in.

**INT: So, the carers give you your medications, do they?**

P07: Yeah. Yeah.

**INT: All of your medications?**

P07: Yes. I did-, nope, not playing games today, is it? I think, it was after you’d been the last time that we were all try-, I was trying to help, but I wasn’t any help was I (*question directed at niece laughing*)?

**INT: Was that with the taking of the photos?**

P07: Yeah.

**INT: So, what about the photo itself? What about the clock in the photo? How does that help you with managing your medications?**

P07: Well, I don’t anymore because they won’t let me (*laughing*).

**INT: So, the carers do it all?**

P07: Yeah. Yeah, I can’t do, you know…

*(Niece advised that how P07 manages her medication had changed since the photos were taken)*

**INT: So, things have changed in the last few weeks since I saw you and brought the camera.**

**So, now the carers manage the medication. Can you tell me a bit about how often you have carers in? How many times do they visit?**

P07: Only about an hour-and-a-half.

**INT: An hour-and-a-half.**

P07: In the evening, they come in here.

**INT: In the evening?**

P07: Yeah.

**INT: Do you have a visit in the morning?**

P07: Yes. Yeah.

**INT: So, twice a day, or is it more frequent?**

P07: No, it’s-, no, because it’s no good me having it. I think, I think-, oh, I don’t want too much, you know.

**INT: So, just twice a day?**

P07: Yes.

**INT: And they help you with pills in the morning and pills in the evening?**

P07: Yeah. Yeah. Yeah.

**INT: And photo number two, that’s got a picture of a box with your medication in it.**

P07: Yeah.

**INT: Are all of your medications in the box or are there any that you have that are separate from the box? Do you remember?**

P07: (*shuffling of papers*) Yeah. Yeah, I think, it was. Looks like it was on the table.

**INT: I remember (***niece***) saying that she took a photo of the word: ‘carer’ written down (***photo number three***) rather than taking a picture of the carer because of the confidentiality issue.**

P07: Yeah. As I say, I think, it’s taken on (*pause*).

**INT: Are you able to tell me what the carers do when they come in to help you with the medication?**

P07: Yeah, they take off the-, hmm. Well, other square- carer in (*focused on content of photo 3)*. I’m not doing very well at this.

**INT: No, it’s fine. Let’s talk more generally and not focus on the photographs. So, we’ve established from the photograph is that the carers help you with the medication from the box ...**

P07: Make her a cup of tea (*speaking to her niece).*

**INT: ... which is where your medications are all laid out.**

P07: Yeah. Yeah.

**INT: So, are you able to tell me a bit more about what the carers do to support you with your medication?**

P07: Yeah, they put them in a glass.

**INT: So, they pop them out of the box, and they put them in a glass for you.**

P07: They-, yeah. Yeah.

**INT: And is there anything else that they do to support you with the medication? Do they order medication, for example?**

P07: Yeah, it comes (*musical* *keyboard sound*). Yeah.

**INT: So, it comes automatically?**

P07: Yes. Yeah. Yeah.

**INT: So, you don’t actually have to do anything?**

P07: No. No.

**INT: And the medications that you take, they’re all taken morning or evening?**

P07: Yes, same.

**INT: So, the carers when they come in in the morning, help you with your morning pills.**

P07: Yeah.

**INT: And in the evening, they help you with your evening pills.**

P07: Yeah.

**INT: So, if we think about the medications, and we’ve just established that you are taking eight different medications, how do you feel about that? How do you feel about the number of medications that you take?**

P07: It’s quite a lot (*laughing*).

**INT: Does that worry you that it’s quite a lot?**

P07: No really. No, it’s for my- yeah, better bits and (*pause*).

**INT: So, you’re OK with it?**

P07: Yeah, it doesn’t worry me really.

**INT: So, no positives or negatives?**

P07: No. No (*laughter*).

**INT: So, in terms of your overarching medications, your eight different medications, can you remember a time when anybody’s reviewed those medications? So, taken a look at them and decided whether you need to continue them or not.**

P07: Yes, I do-, I do, I do need to- to keep them going.

**INT: You do?**

P07: Yeah.

**INT: Do you remember a time when that’s been discussed with a professional? A doctor or a nurse?**

P07: Yes, don’t ask me what for but (pause).

**INT: You can’t remember?**

P07: No, I can’t remember. I can remember the green ones, they’re for your bladder, and (*musical keyboard sound*) (*undecipherable)*

**INT: Do you remember a time when anybody has sat down with you and talked about all of the medications and whether you need to continue them?**

P07: No, I do have a review.

**INT: Who is the review with?**

P07: I’m not sure. Hay fever tablet.

**INT: So, do you know you have the review with? Is that at the GP surgery?**

P07: Yeah. Yeah.

**INT: Is it a GP or is it a nurse, or is it somebody else?**

P07: No, it’s…

*(Niece prompts that it’s the pharmacist.)*

**INT: And how often do you see the pharmacist to discuss your medications?**

P07: I don’t because I have the-, usually the (*long pause*). I know I-, I’ve thought: “oh, crikey”. I have to be very careful with them because they’re quite important else I won’t be taking them.

**INT: So, it worries you a bit without making sure you’re taking them?**

P07: Yeah, I’ve got no choice basically. But, no, no, they’re very good carers.

**INT: What makes you say you have no choice to keep taking the medication?**

P07: Oh, God, it’s so embarrassing.

**INT: No, it’s not. Please don’t panic and take your time.**

P07: Yeah. No, but repeat the prescript…, no um.

**INT: The question?**

P07: Yeah.

**INT: So, you said you felt you had no choice but to keep taking the medications.**

P07: Yeah.

**INT: And I just wondered what makes you say you have no choice? What makes you feel you have no choice?**

P07: I don’t feel nastily I, I must take them. You know, I don’t, I don’t-, you know, we were panicking the other day. She was like- come in and, and, I think: “oh, God, where is it? where ar-, where is everybody?”. Yeah.

**INT: So, it worries you if you’re not able to take your tablets?**

P07: Yeah.

**INT: Are there any of the medications that you would worry about more if you didn’t take them?**

P07: My um, I know they’ve just put me back on Mirtazapine, and I’ve had them for years, and that’s-.

**INT: And you would be quite concerned if you weren’t taking that medication?**

P07: Yeah, I’d rather take-, I said, you know: “you can do it, but I don’t want you taking my tablets away, not at this minute”, you know: “you have to wait or think up something else (*laughing*)”.

**INT: What is it specifically about Mirtazapine that would worry you if you weren’t taking it?**

P07: No, I don’t think so. As I say, I have been on them a long time. I know they’ve only come back-, I know they’re going to-, what worries me is he said on-, on-, now-, oh, don’t worry me, worry me to pass out (*laughing*). I wish I remembered that. (*Niece prompted that they want to reduce it.)* Yeah, that’s their aim. I don’t-, I’d be horrified if they did.

**INT: And why would you be horrified?**

P07: Well, it’s obviously something if they help me to-, for-, how to-, well, I think, they must be a strong medicine, but they haven’t made me feel- but it’s only a couple of weeks, isn’t it?

**INT: So, you’ve only been back on them for a couple of weeks.**

P07: Yeah. Wasn’t it? Wasn’t that? What was it then? (*Questions directed at her niece. Niece prompted that she hasn’t come off them. She has been on them for a long time, and they reduced it a few weeks ago.*) Yeah. Yeah. Yeah.

**INT: And has that changed how you felt since they reduced it?**

P07: No. (*Pause*), I’m very good at taking pills (*laughing*).

**INT: And is there any other medication other than the Mirtazapine that you feel you wouldn’t want to be stopping?**

P07: Umm. (*Pause, sigh*).

**INT: It doesn’t matter if you can’t remember.**

P07: That Citro-, psycho-, whatever it is, antidepressant.

**INT: So, you’d be worried about stopping an antidepressant?**

P07: Yeah. Yeah.

**INT: Why would you be particularly worried about that tablet?**

P07: Well, I don’t know. I’d say such a (*undecipherable words*)-, tablet. Citropan or something or other.

**INT: So, there’s a couple of medications there amongst your eight medications that potentially you might be a bit more concerned about stopping than other ones?**

P07: I don’t worry about any-, any of them. No, I just take the tablets.

**INT: So, if a doctor, like it sounds is happening with your Mirtazapine, was to suggest that you reduce it or maybe stop a medication, how would you feel about that?**

P07: (Pause) Can you repeat that please?

**INT: So, if a doctor, or a nurse, or a pharmacist, if a healthcare professional was to say to you: “we’d like to look at stopping or reducing one of the eight medications that you’re on”, how would you feel about that?**

P07: Oh, I-, won’t worry me because I, I know everybody’s doing their best and (niece) she’s, she’s a diamond (*laughing*).

**INT: So, actually stopping a medication wouldn’t worry you.**

P07: No. I don’t want (*stresses* want) to do it, but I do it because I know I-, you know, I do it. I just I get always so, so stressed and it’s just-. Just looking at me door thinking: “oh, that’s raining out”.

**INT: Yeah, it’s definitely raining out there.**

P07: Yeah, yeah.

**INT: So, thinking back around the medications, if the doctor was to suggest you stopped or reduced a medication. What questions might you have that you’d want answering about that?**

P07: I don’t really know. I don’t go out very much. No, I don’t really-, I don’t really think I-, I know I asked them to stop one.

**INT: And what was your reason for that?**

P07: I think, it was bladder infection.

**INT: So, you were on the medication for the bladder infection?**

P07: Yeah, because I have them quite a lot now, don’t I? (*Question directed to niece, who responds that she does not know what medication she is referring to.*) No, I don’t know which one it is, all I said: “don’t take them off me please (*laughing*)”.

**INT: And why did you not want to stop them?**

P07: I didn’t want them to stop them because I was swinging along nicely, you know, going down a better path than I have been so.

**INT: So, is that a worry that if you stop medications things might change?**

P07: Yeah. Yeah. Yeah, I thought: “oh, no, I couldn’t live without it”. God knows what it was. What it was.

**INT: So, thinking about the Mirtazapine that is being reduced. Do you remember anything about when the decision was made that you would reduce it?**

P07: I was just a-, it’s being a bit selfish. It was a bit-, you know, everybody’s helping me and it’s not what I, what I am. I’m just quite happy sitting watching the telly (*laughing*). Yeah. (*Niece prompted P07 that it was the consultant that wanted her to reduce the Mirtazepine.*) Yeah, but she’d been on before that because-. (*Niece prompted again that it was when they went to see the consultant the other day that he wanted P07 to reduce the Mirtazepine.*) Yeah.

**INT: And was that the consultant in older people’s mental health?**

*Niece prompted that it was.*

**INT: When you were sat with the consultant and he was talking to you about reducing the Mirtazapine, did you have any questions that you wanted him to answer?**

P07: Yeah.

**INT: What questions did you ask him?**

P07: I-, well, I just wondered what was going on or-, you know. Quite stressful. Although your scrip-(*struggled to find the word*s).

**INT: And when the decision was made to reduce that medication, has any plan been put in place to monitor that? Any changes that happen?**

P07: Well, I don’t know. I don’t think so.

**INT: Would you want there to be?**

P07: Tell me that again.

**INT: What would you want to happen now? What do you want to happen now from the perspective of the consultant who made that decision?**

P07: Yeah. Yeah. I don’t want them taken away, the tablets. Not-, I mean hay fever, yeah, you know, but-, you know, I don’t want to stop the tablets because I don’t know what state I’d be in without them. ‘Cause I-, you know, you lean on, don’t you? And hopefully it will last a few years. I don’t know if it’ll be that long.

**INT: So, it sounds like your concerns are if they’re stopped that things might change from how they are now, it might get worse.**

P07: Yeah. Yeah.

**INT: So, if, as the consultant has done, they’ve made a decision to try and reduce a medication, how is it best that they follow that up to make sure that you’re not getting worse?**

P07: Yeah. I mean, I don’t-, you know, go out and about, do we (*niece*)? And it’s, yeah, I don’t know. (*Niece prompts that P07 is left in limbo, because there is no actual outcome from it.*) Yeah.

**INT: So, they just reduced it and no follow-up telephone call to say: “how are you feeling?”.**

P07: No.

**INT: So, do you feel a bit in limbo?**

P07: Yeah.

**INT: So, when that decision was made, did you feel that you were part of that decision-making, that the decision-making was shared with you? So, your view was taken into consideration?**

P07: No, wouldn’t do that. (*Niece agreed, advising that they were told rather than there being any discussion.*)

**INT: So, it was very much healthcare professional decision rather than involving either of you?**

*Niece prompted that this was the case.*

**INT: Do you think you should be involved in those decisions?**

P07: Well, I’d like to think I would be. Yeah. Yeah.

**INT: But your experience is that that doesn’t happen, or does it sometimes happen?**

P07: No, I-, I just battled along and it’s hard work. Very hard work. I mean, our parents died when they were fifty, you know. So, things like that, I mean, there’s no-, she’s never going to come back, or my dad, you know. It would be nice to see-, if you could just have them for a day. Yeah. (*Long pause*)

**INT:** (*Pause)***So, when the Mirtazapine was stopped by the consultant, were you told what you might need to look out for?**

P07: No (*pause).*

**INT: So, you’ve mentioned that it might be helpful to have some form of follow-up.**

P07: Yeah.

**INT: Have you any views on what that follow-up should look like? Should it happen face-to-face, over the telephone? Any thoughts about how that might happen, in an ideal world, if it was going to happen?**

P07: Yeah. Ah, that’s hard one.

**INT: How easy is it for you to have a conversation about your health needs with a healthcare professional on the ‘phone? Is that something you find easy?**

P07: Yeah.

**INT: Or is it difficult?**

P07: Yeah. No, I am quite happy on the ‘phone.

**INT: So, you’re happy to do things on the ‘phone or would you prefer things face-to-face, which might be easier?**

P07: Yeah.

**INT: Any particular views?**

P07: No. Can you think of anything? (*Question directed to her niece, who prompted that was P07’s view that was wanted.).* Oh, it’s about me, and I wish it wasn’t (*laughter*).

**INT: That’s not a problem. So we’re going to go back to how you manage your medications, and we know that you’ve got your box of medications. So, when that decision was made to start to reduce your Mirtazapine, has that caused any problems with your boxes?**

P07: Oh. (*Prompted by niece that P07 just takes what is in the boxes, with the dose reduction left in the hands of the GP and the chemist.*). Yeah, it’s left like in a, a Nomad, that’s all.

**INT: Do you get a four-week supply, a two-week supply? Do you know?**

P07: (*sigh*) I do (*laughing*). Umm, no, I don’t know. *(Niece prompts that it is weekly).*

**INT: You get them weekly. OK. So, if they’re coming weekly that means that it doesn’t cause too much of a delay if something is being changed.**

P07: No. No.

**INT: So, that’s been really helpful because you’ve given us some really good insights into your views.**

P07: Yeah.

**INT: Is there anything else relating to stopping medication that you want to tell me about?**

P07: Yeah. I’m just not very happy.

**INT: You’re not very happy about stopping medications?**

P07: No. No, I used to like my Mirtazapine when I was down in-, we come from (*city*), and-er, we were on there quite a long time (*laughing*) so (*pause*).

**INT: So, the length of time you’ve been taking it…**

P07: Disappeared and, and then I got back on it. I didn’t have trust in the other one, that--- what was it, co-, co-… (*Niece interjected to question whether she had been on Mirtazepine/antidepressants when she lived in (city), which was as a young girl*). Yeah. To meet my needs really, but as long as everything’s going along smoothly, I’m not expecting to go up there. Yeah.

**INT: So, there is some worries around stopping medications?**

P07: Yeah.

**INT: And a kind of trust in the medication.**

P07: Yeah. We have got a senior consultant down there-, the hospital, (*hospital*). Oh, (*struggles with hospital name*). Oh, my God (*laughing*). (*Hospital2*). (*Hospital2*).

**INT: That’s where you see the older person’s mental health team, isn’t it?**

P07: Yeah. Yeah.

**INT: Anything else you want to add?**

P07: No, not really. As I say, those are the two main-, I don’t know what the others are, but-, you know. (*pause*) No, I haven’t. I haven’t. Sorry.

**INT: No, please don’t apologise. That’s been really helpful.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

P07 Respondent

***Audio* file: 29.49 minutes**