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

Transcript for interview

**P08**

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

**INT: So, if we start by looking at the photos.**

P08: Yeah.

**INT: Firstly, I know that you took the photos yourself, but did you plan what you were going to take, or did you do it a bit more spontaneously?**

P08: A bit spontaneously really. I thought: “I must take these photos”. Yeah.

**INT: Then you just took them.**

P08: Yeah.

**INT: Let’s talk through each photo in turn. So, if we start with the one that I have labelled up as photo number one, can you tell me a bit about that picture and what it tells us?**

P08: Well, I tried to keep them in one place in order. I keep the spare ones-, I try to keep it simple because I’m-get confused. I keep the spare ones upstairs in my bedroom on the shelf so, and I try to bring them down as and when necessary, and I keep them in this box and then I decant them into the dispensing box once a week.

**INT: So, that’s photo number two.**

P08: Two, and the box is also there.

**INT: Yeah, and it’s on photo number one, isn’t it?**

P08: Yeah, it’s trying to keep me straight until I get frustrated because I haven’t ordered a continuing- con- the next dose, the next, the next packet.

**INT: So, you fill the box up once a week?**

P08: Yeah, and when I can-, not this week because I’ve run out of two things which they’re going to try and get for me. Normally it works, sort of. Well, not very well but I’m getting better at it. Since I’ve had many more packets to keep an eye on, but it’s quite a headache, but I don’t, I don’t find these folder things any good where you tick-off something every day. Do you know what I mean?

**INT: Yeah.**

P08: I don’t think they’re any use, to me anyway. Maybe if you’re just taking one or two pills, it’s useful to tick them off every day, but it’s just an additional faff really.

**INT: So, you don’t use that?**

P08: No. No.

**INT: I can see that in photo number one, and photo number two, one of your boxes has got what looks like a post-it attached to it.**

P08: Yeah.

**INT: Can you tell me a bit about that?**

P08: That probably-, it’s the same box, isn’t it?

**INT: It is, yeah.**

P08: I can’t remember what that says now. Do you want me to have a look?

**INT: No, but is it some kind of reminder?**

P08: A reminder. Yes. Yes, I can’t remember what it reminds me now though which is not very helpful, is it?

**INT: But you tend to use little post-it’s like that to remind you of things?**

P08: Yes. Yes, occasionally. Yeah, I think, they’re a bit straightened out now. I haven’t-, not to-, I could go and look and see if you like.

**INT: No, we can have a look at the end.**

P08: OK.

**INT: What about photo number three?**

P08: Well, I think, that was a bit of a mistake really, but that is where I, I keep them and I bring them down to here, and I try to keep that clear for my ‘phone, and the tablets above. So, I try to keep it in one place and not spread it round the household.

**INT: So, they’re out on the table when you’re filling your box.**

P08: Yeah.

**INT: And then they go back into the cupboard.**

P08: Yeah. Yeah.

**INT: And I wondered if there’s any significance to the i-Pad that’s there?**

P08: Well, I try and keep that charged up there. I like my-, it’s sort of like a little office, almost, you know, I, I know where things are. So-, because I get muddled up if I’m not a bit-, I try not to get muddled up really, and (*family member*) is a nurse and she’s a bit super-effi-, oh, I shouldn’t be saying that. Anyway, she’s very efficient so, I try to keep things straight, but I don’t see them very often so. She has been very helpful at times sorting me out.

**INT: So, keeping things in one place is one way of just making sure you know where things are?**

P08: Yeah, keeping on top of it. Yes. Yeah. Yeah.

**INT: So, in terms of managing your medications, you’ve mentioned filling-up the box once a week.**

P08: Yes. Yeah.

**INT: Bringing down the tablets from upstairs when your packets are getting empty.**

P08: Yeah.

**INT: What else do you do day-to-day/week-to-week in terms of managing your medications?**

P08: (*pause*) I can’t-, such as what?

**INT: Well, you mentioned ordering. Tell me a bit about how you order the medication.**

P08: I try to-, if I’m running low, I try to take a prescription request over to the surgery and then after about three days or so, or more, it might be ready at (*name of pharmacy*). But it doesn’t seem to be much telling how long it takes for them to pick it up and-, in fact, I had a query the end of last week with-, you-, I don’t-, I think, it’s a nurse who answers the ‘phone to see whether you need an appointment or not, and she answered some query of mine, but I’ve never had the answer. So, occasionally you’ll get a complete blip where-, and now, I can’t remember what the question is even. So, is that what you asked me? Sorry.

**INT: Well, I was just asking you about other things that you do to manage your medication and ordering medication.**

P08: Right, well that, that sort of thing.

**INT: So, do you have to order your medication on a regular basis?**

P08: Well, they come at different times. I run out at different times, and in fact, I ran out of the one that stops me feeling so sick and dizzy, and I, I rang 111 and they, they exhausted me, exhausted me, quizzed me about how I was and, I think, she thought I was-, no, she didn’t, but she asked me lots of questions and cross-questions, and then put me onto a doctor a bit later on. And he rang and said I did need the tablets, so they were ready next morning, but I could have gone that night if I could have got out at night, and picked them up, but I didn’t need them that urgently, you know.

**INT: So, a problem seems to be from what you said, that the tablets run out at different times. Therefore, keeping on top of them is quite tricky.**

P08: Yes. Yeah.

**INT: I think, when we met a couple of weeks ago you mentioned about some come through automatically.**

P08: Yes. Yeah.

**INT: And some you have to order.**

P08: Yeah.

**INT: Tell me a bit about the difference between those?**

P08: Well, I, I don’t know which is which, to be honest, but then I go to (*name of pharmacy*) and they say: “oh, it’s- it’ll be in”. You know, like my grand-daughter’s got this Fortisip for me yesterday because, you see, I can’t bring it home myself, and they said: “no, you can’t have it until Wednesday” when a new prescription-, they told (*name*), grand-daughter, that you have to sort of wait until it’s- well, until it’s-, until they’ve got it in really, to be fair. You know, if they haven’t got it in, they can’t-, they can’t give it to you, can they? So.

**INT: But some pills they automatically do for you.**

P08: Yeah.

**INT: And others they don’t.**

P08: Yeah, and you end up sometimes with a big collection, you know, last, last- enough to last you a couple of months and then, you know, you run out of other things. I think, I’m getting better at realising what’s coming automatically and what’s not, but there’s about- no, eight or nine things and my head can’t cope with it sometimes (*laughter*).

**INT: So, the automatic ones, do they come through every month, every two months? How does that work, do you know?**

P08: Well, I don’t know, they just appear. I-, honestly, I’m sorry to be a big vague but they’re, they’re just- and then sometimes you’ll get a big bag of things and, you know, and other times, a little tiny bag with one thing in it so.

**INT: And those are delivered to you, are they, or do you go to pick them up?**

P08: I go to (*name of pharmacy*) to pick them up. Yes. Yes.

**INT: So, is there anything that might help with those ordering problems that isn’t already in place?**

P08: (*pause*) I suppose, I should make a note of what I’ve got, would be a help, wouldn’t it, or when I don’t need-, when I go in and say: “I’ve, I’ve got loads of this, I don’t need any more”, and they keep it or something, but most--, I think, it’s- like eye drops, I’ve got enough eye drops to last me a couple of months, but the trouble is you go-, obviously, they give it to you in a sealed packet and you don’t know what you’ve got until you get it home. I could open it and check of course, but I don’t. So, yeah. So, it’s a bit muddling, but I’m kind of easily muddled at the moment.

**INT: So, you mentioned that you’re taking nine medications, how do you feel about the number of medications that you’re taking?**

P08: Well, I think, they’re doing me good. I think, they’re all helping, as far as I can tell, you know. I certainly know if I haven’t got the anti-dizzy one, I feel horrible without, you know, that seems to be working. And two of the GPs I’ve seen have been extremely helpful, they spent a long time, you know, sorting- going through things with me so.

**INT: So, you don’t feel that there’s any particular issues with the number of medications that you’re taking?**

P08: Not really and, I hope, they’ve checked they all agree with each other. Yeah, I get-, take most of them at eight’ish in the morning with my breakfast and then I take a couple lunchtime, a couple suppertime, and I’m reminded about those because I start feeling dizzy so, that reminds me to take the pills if I want to have supper or something. Yeah.

**INT: So, you always tend to take them with a meal?**

P08: Hmm. Yeah.

**INT: But the reminder for that comes from how you’re feeling.**

P08: Yes. Yeah. Yeah.

**INT: So, you mentioned there about whether medications are OK altogether.**

P08: Hmm. Yeah.

**INT: Can you remember a time when you’ve had your medication reviewed? So, when a healthcare professional has reviewed your medication?**

P08: I suppose-, when I’ve been to see the GP, I suppose. I don’t remember her- either of them specifically going down the list, but presumably they do because they look at-, you know, they refer to it, don’t they? When you’re sitting there, they refer to what you’re taking so.

**INT: But you can’t remember a time when specifically your medication has been looked at?**

P08: I don’t remember being called in and they said: “we’ll go through your medicines”, but I- presumably, I shout if I need- something’s not working, I, I shall say-, I shall shout, I shall ask for help, I suppose. Does that make sense?

**INT: Yeah, that does make sense.**

P08: Yeah? OK.

**INT: So, sometimes it can be decided that a medication is not needed any more or for different reasons, you know, it might be that it is interacting with something else or it could be that actually, they just don’t feel that you need it anymore.**

P08: Yes. Yeah. Yes.

**INT: What’s your view about stopping medication? How do you feel about stopping medication?**

P08: Well, I, I have faith in the doctor. If they stay stop, I will stop.

**INT: You’d stop.**

P08: But I would try to discuss it with them but, I think, I think, most of the doctors over there will discuss things with you if you give them a chance or ask them to. Yeah.

**INT: So, if they were to suggest that you stopped a medication, what sort of information might you want?**

P08: Well, I’d ask why, I suppose. Yeah, and I hope I get a (*laughing*) sensible answer, you know. Yeah.

**INT: Would you see that as a normal part of managing a health condition, potentially stopping a medication, or do you see it as something a bit unusual?**

P08: I think, it’s a normal part. You don’t want to take pills unnecessarily. Yeah.

**INT: And of your medications that you’re currently taking, are there any medications that you would have more concerns about stopping than others?**

P08: I would be concerned about not having the dizziness one, whatever it’s called. Do you want to know what it’s called?

**INT: No, that’s fine.**

P08: You probably know anyway, but-, I’ll be concerned not to have the laxative ones, I think, I’d be, be in a bit of a problem without those. But the others, I take because it’s suggested I take them, and I trust it’s for my own good, you know.

**INT: So, the dizziness one, the reason for not wanting to stop is?**

P08: Because I feel it’s doing me good (*laughing*).

**INT: And your medications that you’re currently taking, do you see anybody apart from your GP about those or is it all under the care of your GP?**

P08: No. Well, I might-, my son being a surgeon and my daughter-in-law being a fairly senior diabetic research nurse, they know lots, and they might say: “what-, how are you doing?, what are you taking?”, but they don’t advise me, but they, they might, they might say: “have you asked about so-and-so?” or, or they’ll say what they’re for, but they wouldn’t, they wouldn’t counter the GP’s advice, they’d just be looking after me really, and they’re being very kind to me. Yeah.

**INT: And can you remember a time in the past when a medication that you’ve been taking has been stopped?**

P08: Oh, they’ve just taken a box back to the surgery, something that was stopped, and I can’t remember what it was now.

**INT: Can you remember what it was for?**

P08: I think, they changed it for a better one.

**INT: So, they stopped it and replaced it with something to do the same job?**

P08: Yes. Yeah. Yeah, sorry, they’ve just gone with the box.

**INT: Don’t worry.**

P08: Yeah, I can’t remember what it was. Sorry.

**INT: But it was a replacement as opposed to a stop completely?**

P08: Yes. Yeah.

**INT: Have you ever stopped a medication completely?**

P08: I don’t, don’t think so. I don’t remember. I’ve never been on so many so, hopefully, I shall be sorted out and won’t need to take so many sometime, I, I don’t know when.

**INT: And the medication that they’ve changed so, they’ve stopped, and they’ve replaced it with something else, were you involved in the decision-making about that? Were you involved in a discussion?**

P08: Well, I, I suppose, they just said: “well, we’ll prescribe so-and-so instead of that one” but I don’t- I, I have no opinion really on, on that.

**INT: So, you weren’t really involved in the decision-making?**

P08: No.

**INT: So, if we go back to if somebody suggested that a medication might be stopped, what do you think the best way is for that to happen? How would you like to be told about that? What would you like to happen?**

P08: I’d like them to explain why (*pause*). I mean, just have faith in the GP that they, they know what’s best really.

**INT: So, you’ve mentioned the GP, would you consider the GP the best person to do that or are there any other professionals that you might think would be good to be involved in those sorts of decisions?**

P08: No, not really, unless say, say after a hospital consultation but then it would be a, a medical one again, wouldn’t it? Yeah.

**INT: So, you would see as it being the domain of the doctor?**

P08: Yeah.

**INT: And you’ve already mentioned that you would want to be involved in that decision-making. Would you want anybody else to be involved?**

P08: No, I don’t think so. I’m not sure what you’re getting at really.

**INT: Just a very open question. Some people would say: “yes” some people would say: “no”, would you wish for anybody else to be involved?**

P08: I don’t think so because who, who would have better information? I mean, if I’ve got eight different things that I wouldn’t know, nobody else would know, unless I went through them, and the dosage, nobody else would know better than the GP really.

**INT: And would you want anybody to be there to support you with the decision-making?**

P08: I have- (*son*)’s been with me a couple of times, but that was helping sort me out, maybe two months or so ago, and he asked all sorts of questions which was brilliant. And they got the-, the GP and (*son*) got on very well, and straightened a few things out in his, his mind as well, what was happening.

**INT: So, it was reassuring for him as well as for you?**

P08: Yes. Yes. As I say, he, he in no way was questioning her ability, it was just he was perhaps asking a few deeper questions which reassured him. Yeah. Yes. Yeah.

**INT: So, he was getting the answers that he needed as well as the answers that you needed.**

P08: Yes. Yeah. Yeah.

**INT: And so, you’ve mentioned in terms of the information that you would need you’d want to know why. Is there anything else that you would want to know if the suggestion was made that a medication was stopped?**

P08: Not really, I don’t think. No.

**INT: And is there anything that would help you to share that decision-making with the professional so that you came to that decision together?**

P08: I don’t know. I mean, I could ask questions. Is that-, that’s-, is that what you’re thinking?

**INT: Well, I’m not thinking anything (*laughing*), it’s your views again.**

P08: Yeah, I, I feel I can ask the GP’s I’ve seen questions.

**INT: Is there any specific or anything particular about the GP that makes you feel comfortable to ask questions?**

P08: They usually seem relaxed and have time to spend. The real bugbear is you can’t get an appointment very quickly, you know, which doesn’t make you feel any better.

**INT: But when you do get the appointment, you have the time?**

P08: Yeah. Yes.

**INT: And do you tend to see the same GP, or do you see different GP’s?**

P08: Well, I, I, I have learnt to ask for the same GP the last- twice, I think. In fact, there’s two, both of them ladies, that I found are very helpful more than the men say. Maybe I’ve just not hit on the right men so. I don’t know.

**INT: Is there any kind of timing of making decisions about stopping medications that would be important?**

P08: I would take the GP’s advice on it, I think. Yes. Yeah. Yeah.

**INT: So, if it has been advised that a medication’s been stopped, you’ve had that discussion and you’ve agreed that this medication is going to stop. What do you think should happen then?**

P08: I think, I might like a follow-up, but you see that would be in ten days, eight/nine days’ time which might be-, if you stop something, you might need to perhaps go back on it or not, so.

**INT: So, eight/nine days, is that too long or too short?**

P08: It could be. I’m just having a little worry that it could be. If you stop something, you might not feel so good, you might need to go back on-, on the other hand, you might be: “good, good riddance, that’s one gone”, you know.

**INT: So, maybe a sooner follow-up might be needed?**

P08: I think. Yes. Yeah. Yeah.

**INT: And what should that follow-up look like? Would it need to be back at the surgery? Could it be by ‘phone?**

P08: I expect it could be by ‘phone really providing you could then get an appointment face-to-face and not have to wait over a week/ten days (*knock on the door*).

**INT: So, that sounds like a worry to you.**

P08: Yes, it is. Hello (*male talking in the background*).

***Recording temporarily stopped and restarted.***

**INT: So, we were just talking about follow-up.**

P08: Yes.

**INT: And there was a bit of a worry there about potentially not being able to get the face-to-face follow-up quick enough if you needed it.**

P08: Yeah, if you needed it. Yeah, it’s a big: ‘if’ really.

**INT: And that’s a worry?**

P08: A little worry. Yes. Yeah, not a big one. Yeah.

**INT: And if they suggested stopping a medication, what sort of follow-up would you be looking for? Is there anything specific you’d be looking for in that follow-up?**

P08: Well, just to be able to talk about it and answer any questions that I might-, they might put to me, or I might put to them just in time really. See, over at the surgery, I think, when you ring for a, an appointment, you often get advice over the ‘phone but it’s not a GP, GP, it’s a nurse so, it’s not always-, as far as I know, you know.

**INT: So, would you want that follow-up to be with the GP?**

P08: Well, preferably. Yes. Yes, because of the time-lag all the time, you know, but then I-, they’re under pressure so. Yeah.

**INT: So, what would your concerns be about having that follow-up with a different professional?**

P08: That would be alright.

**INT: It would be OK.**

P08: Preferably the one-, well, I, I don’t know, sometimes it’s better to change, isn’t it? Preferably with the one who, who knows you, I think.

**INT: So, if we go back to your ‘photos. Photos number one and two. How might stopping a medication impact what you do on a day-to-day/week-to-week basis?**

P08: I don’t know, I just take them out of the box and throw them away.

**INT: So, if the doctor was to say today: “you need to stop this one”. You would go through and take them out?**

P08: Yeah. Yeah.

**INT: So, you can’t see it having a big impact or would that be a big impact?**

P08: Not, not really, I’d be quite glad to take-, to have less, you know, to sort out really.

**INT: So, stopping medications in terms of the numbers of medications isn’t too much of a problem?**

P08: No. No (*laughing*).

**INT: So, is there anything else about stopping medication that might worry you?**

P08: No, I don’t think so, providing I could talk to somebody about it, and possibly start it again if necessary. I can’t see any problem about that. No.

**INT: And what might tell you that it would be necessary to start again?**

P08: When you get the symptoms back you had before you, you know. Yeah.

**INT: And is there anything else that you want to add to what we’ve already said stopping or reducing medication?**

P08: I don’t think so. As long as I felt it would be a good thing, but then the GP would have to tell me that it was a good thing, you know, I’d need professional reassurance really. Yeah.

**INT: Okay, so, that’s all my questions. Let me turn off the recorder.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

P08 Respondent

***Audio* file: 28.10 minutes**